CHILDHOOD CANCER REGISTRATION

International Agency for Research on Cancer
Lyon, France

Eva Steliarova-Foucher

ENCR-JRC Training on Cancer Registry Data Collection and Comparability

3-4 May 2017, Ispra, Italy

Content of the childhood cancer session

1. Introduction to childhood cancer registration: differences in data collection from adults
2. Collecting long-term follow-up data on children with cancer
3. ICCC-3 update
4. Interactive exercise 6: Evaluation of a childhood cancer dataset

Structure of the childhood cancer session

Session 1: General introduction

- Incidence
- Mortality
- Survival
- Long-term survivors

Session 2: Data collection

- Long-term effects data collection
- Staging
- Classification

Session 3: ICCC-3 + data quality

- ICCC-3 principles
- ICCC-3 update
- Data quality assurance and evaluation

Session 4: Interactive exercise 6:

- Evaluation of a childhood cancer dataset

Session 1

INTRODUCTION TO CHILDHOOD CANCER REGISTRATION

International Agency for Research on Cancer

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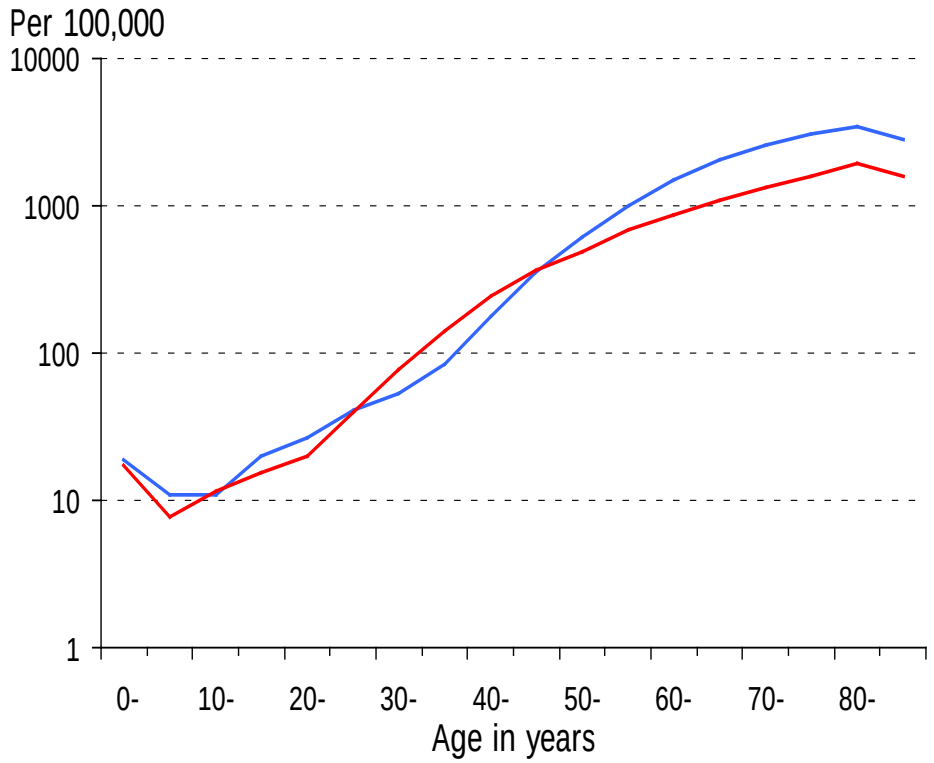
Age-specific incidence of cancer



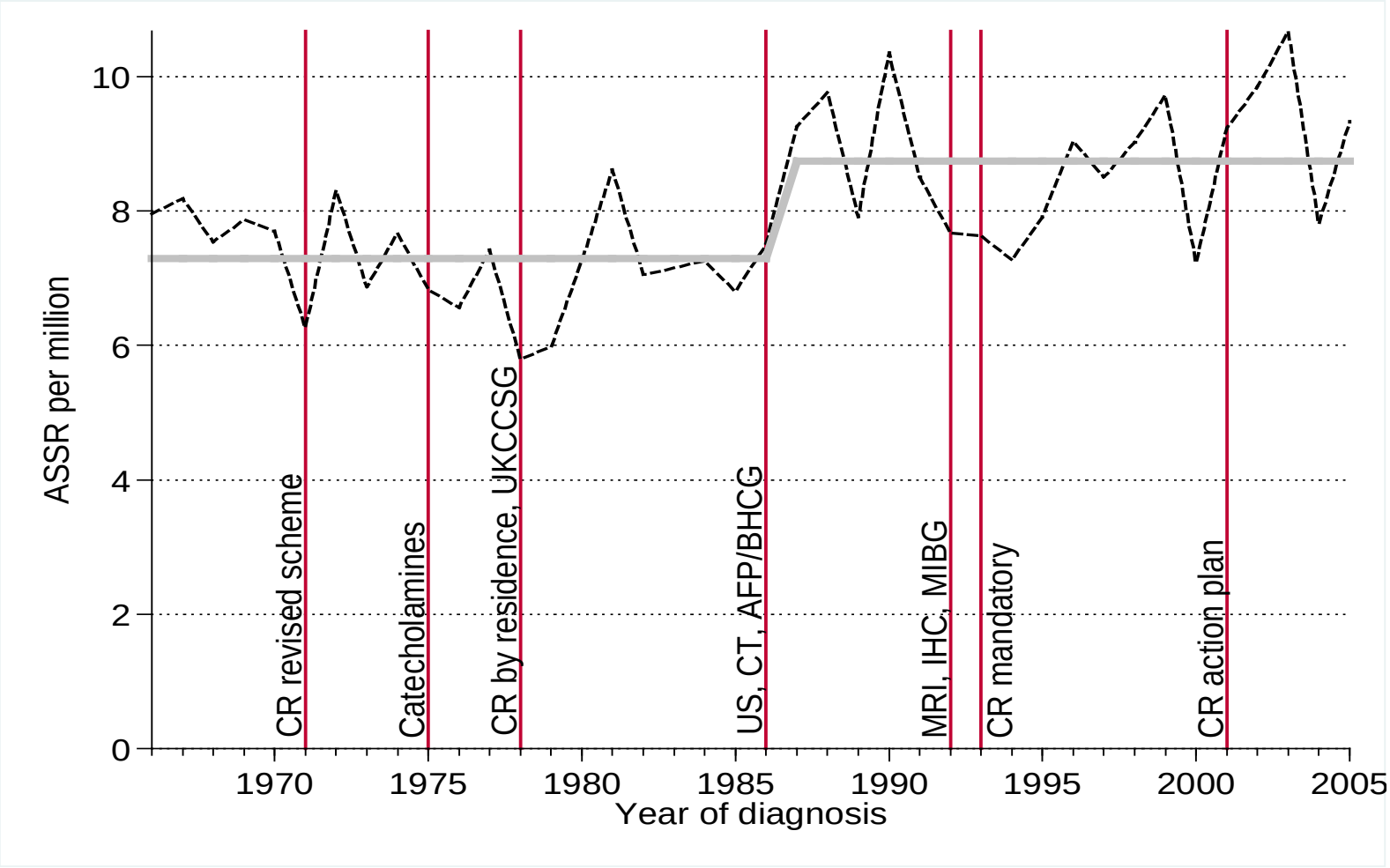
Slovakia, 1988-2002

Source: Cancer Incidence in Five Continents, volume IX

Risk of getting cancer:
1 in 500 persons before the age of 15 years
1 in 300 persons before the age of 20 years
(1 in 5 persons before the age of 65 years)

Incidence Trends in Great Britain

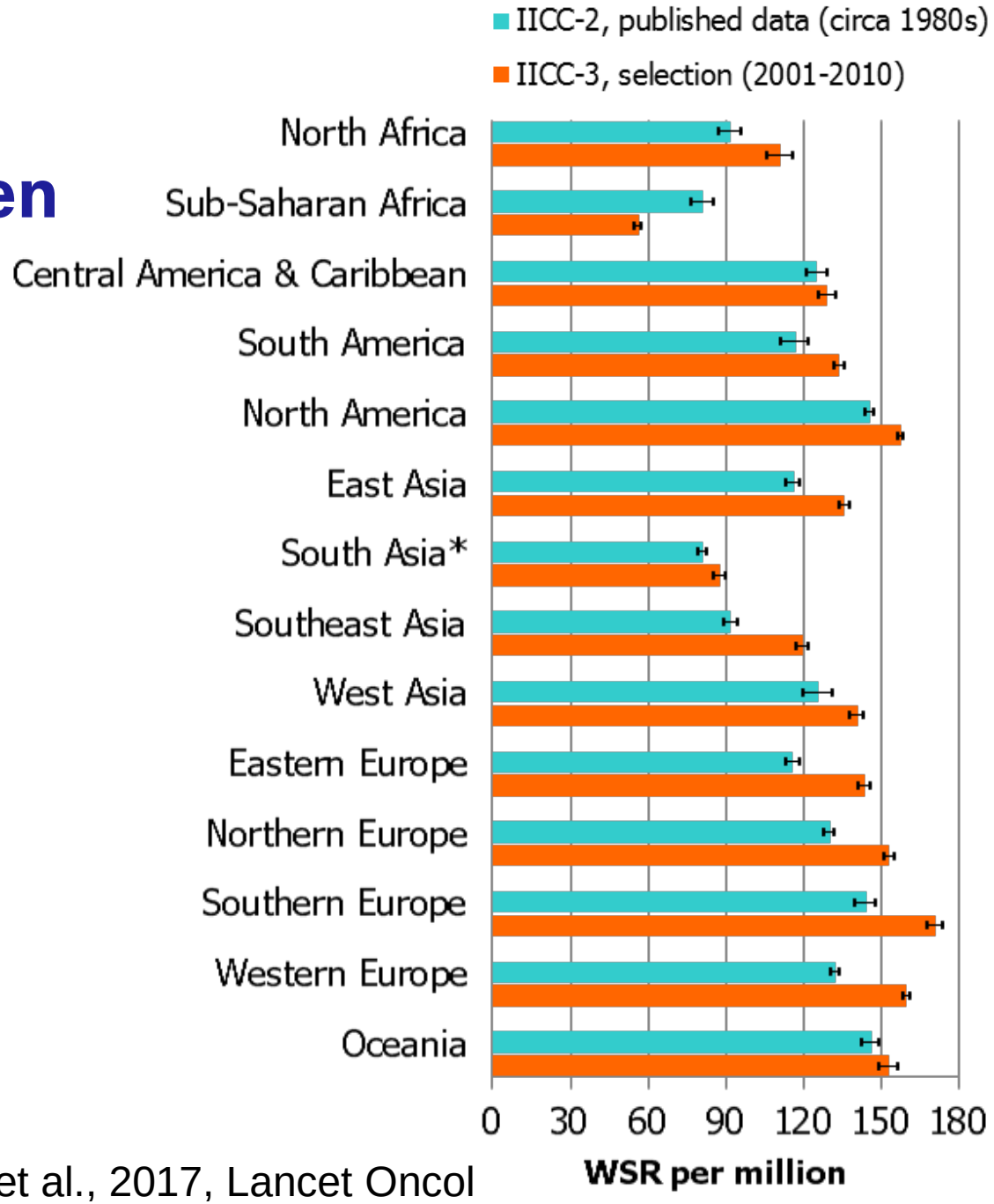
Courtesy of Charles Stiller



Recorded incidence of neuroblastoma in children (age 0-14), Great Britain, 1966-2005
Actual (dashed), step model (solid) line

Kroll ME et al. Effects of changes in diagnosis and registration on time trends in recorded childhood cancer incidence in Great Britain. *Br J Cancer* 2012; **107**:1159-1162

Age-adjusted incidence rates of cancer in children aged 0-14 years



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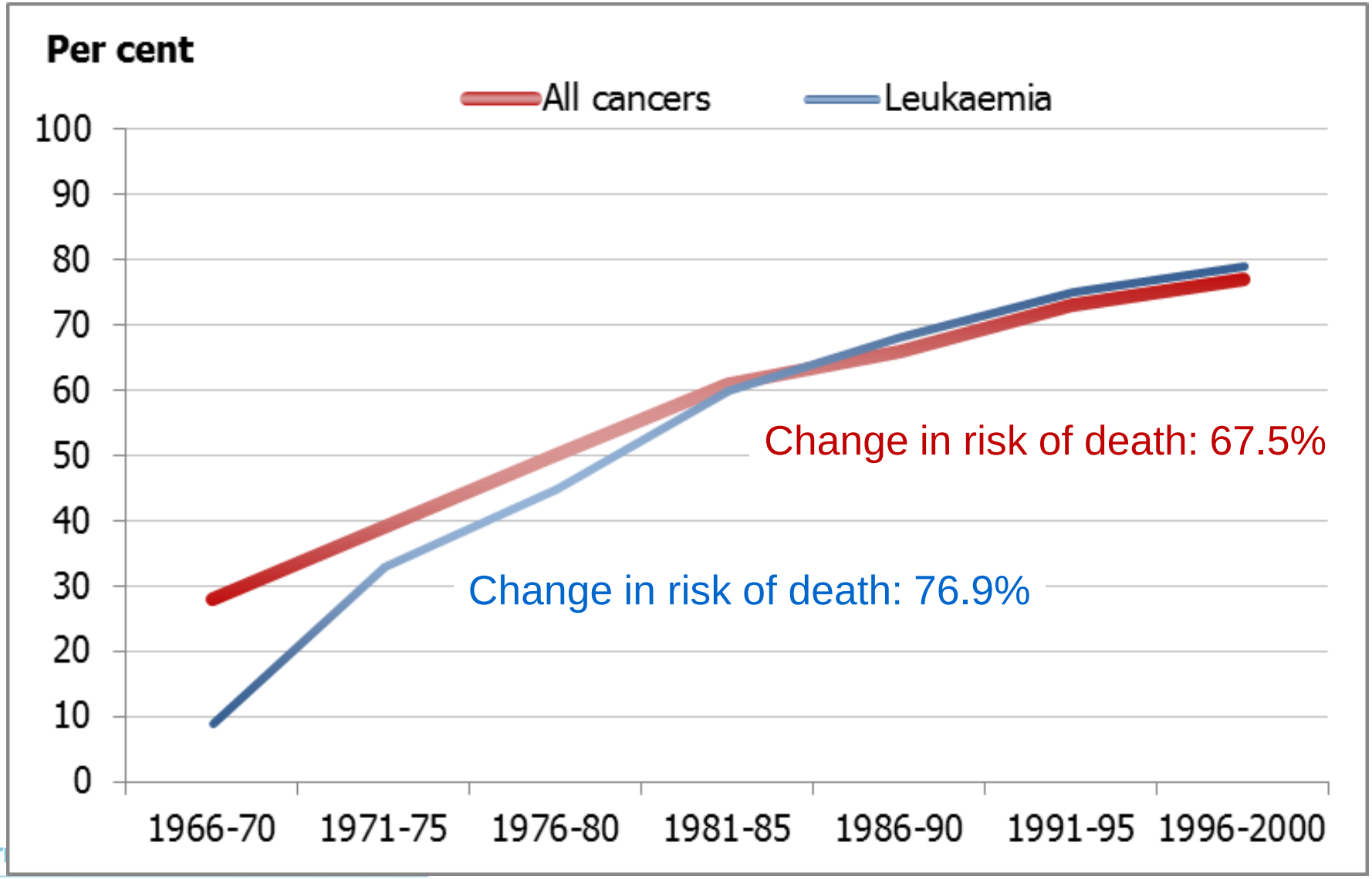
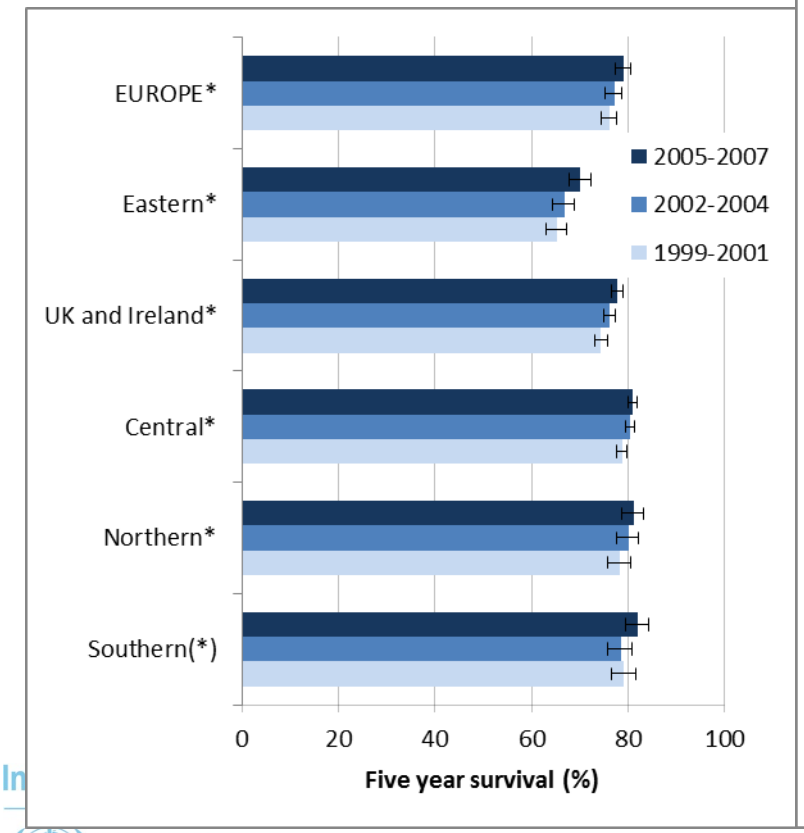
Steliarova-Foucher et al., 2017, Lancet Oncol

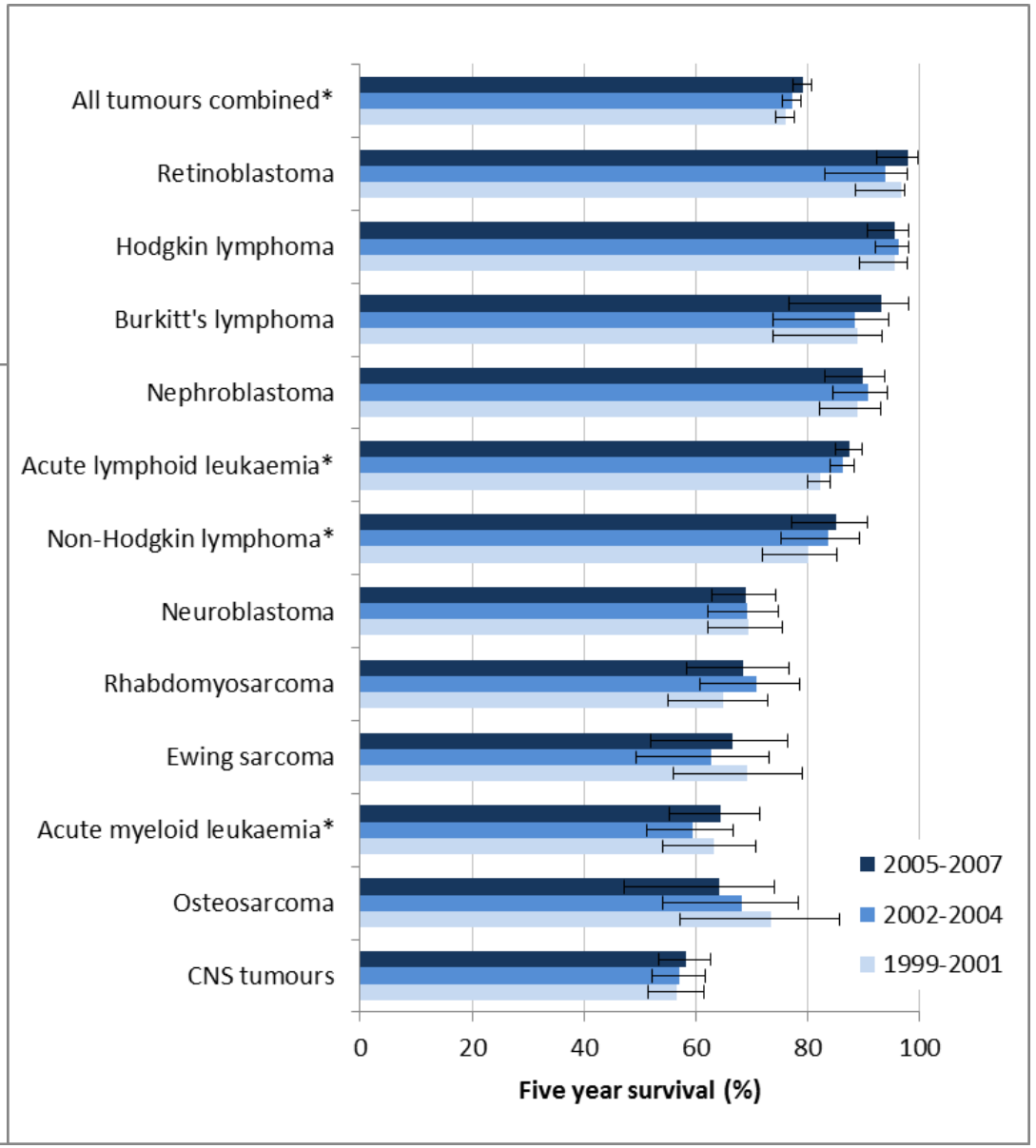
5-year survival of children with cancer in Britain



UK National Registry of Childhood Tumours: Stiller et al., 2007

Survival of children with cancer in Europe (age 0-14)

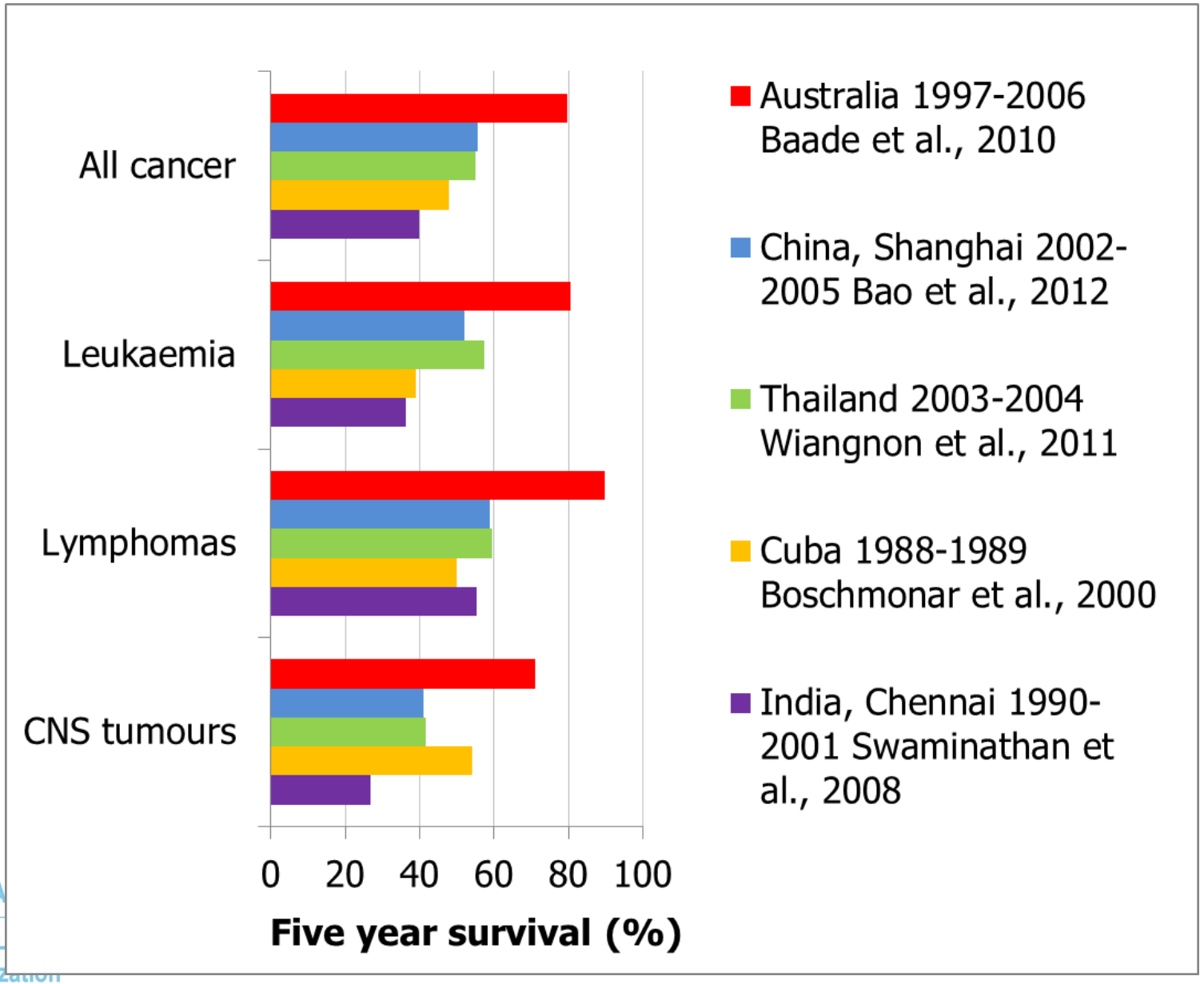




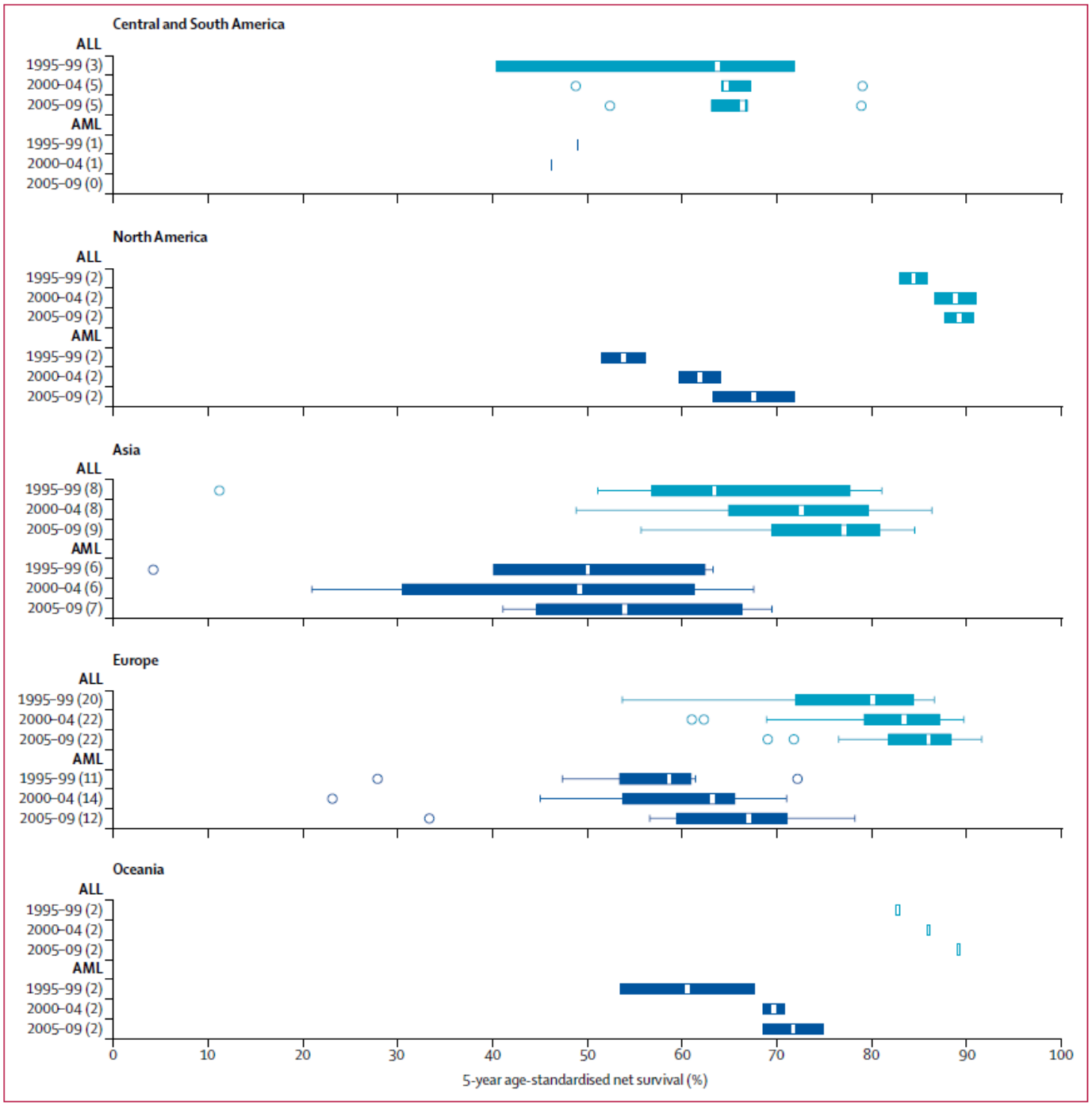
World Health Organization

Source: EUROCARE-5 (Gatta et al., 2013)

Survival of children with cancer (age 0-14 years)

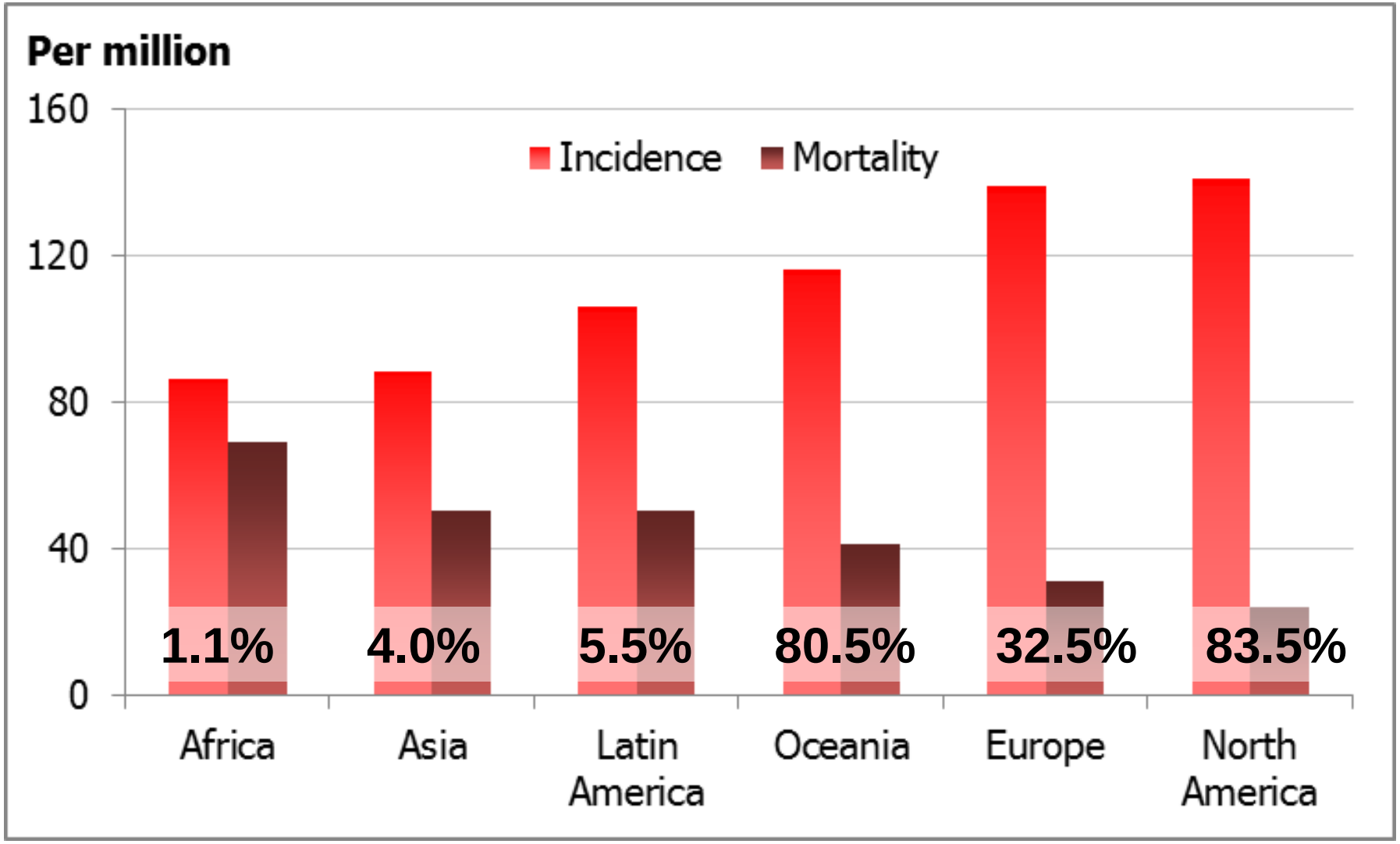


Survival of children (age 0-14) with leukaemia



Bonaventure et al., 2017 Lancet Haematol

Childhood cancer rates



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Source: Globocan 2008: Ferlay et al., 2008:

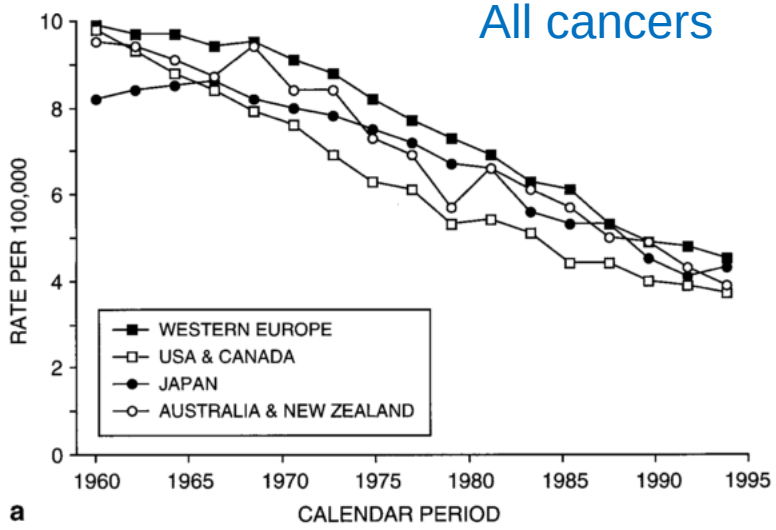
Mortality rates in age 0-14 years

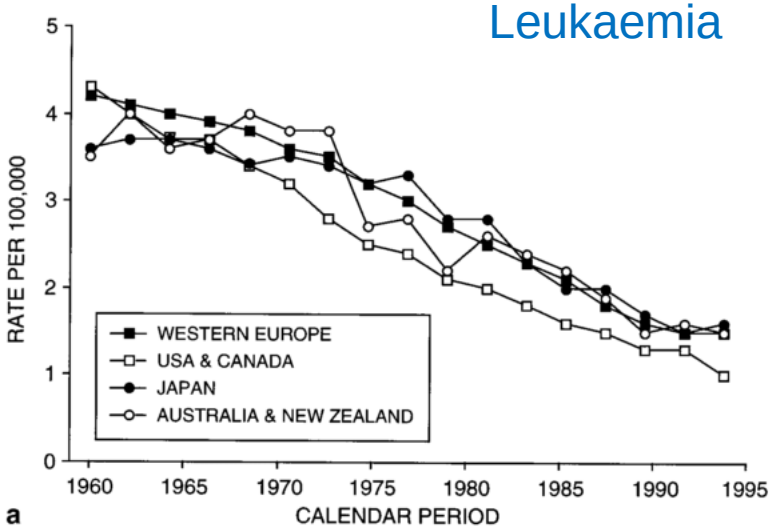
All cancers

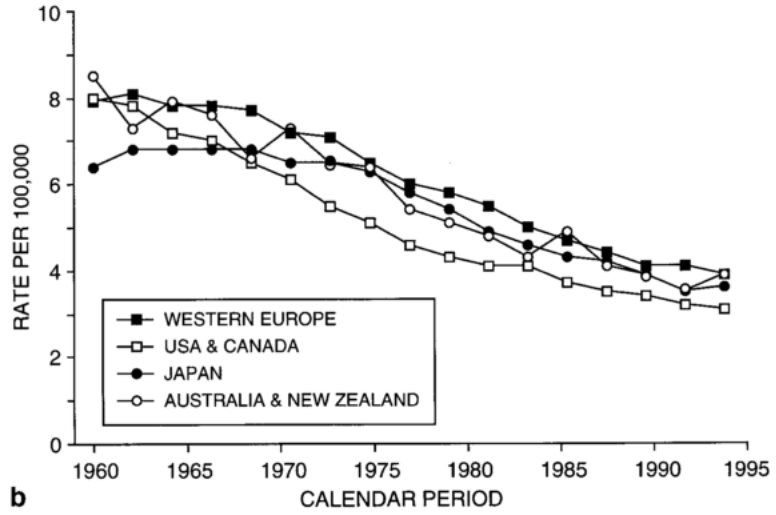
Leukaemia

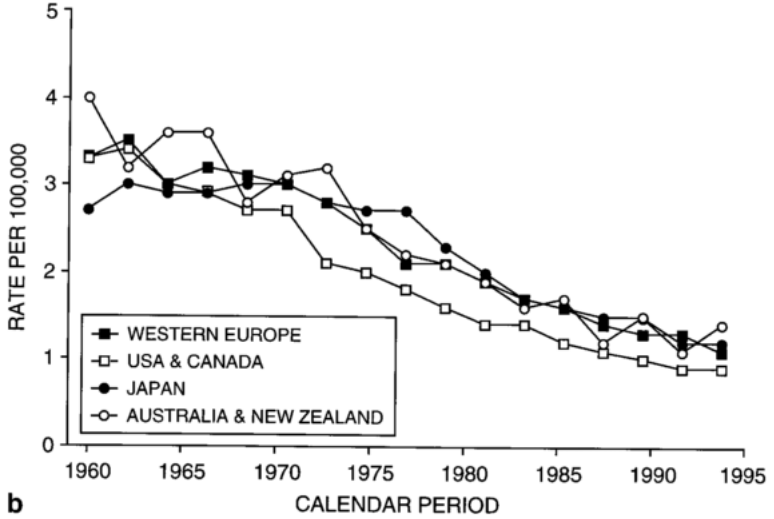
Males

Females









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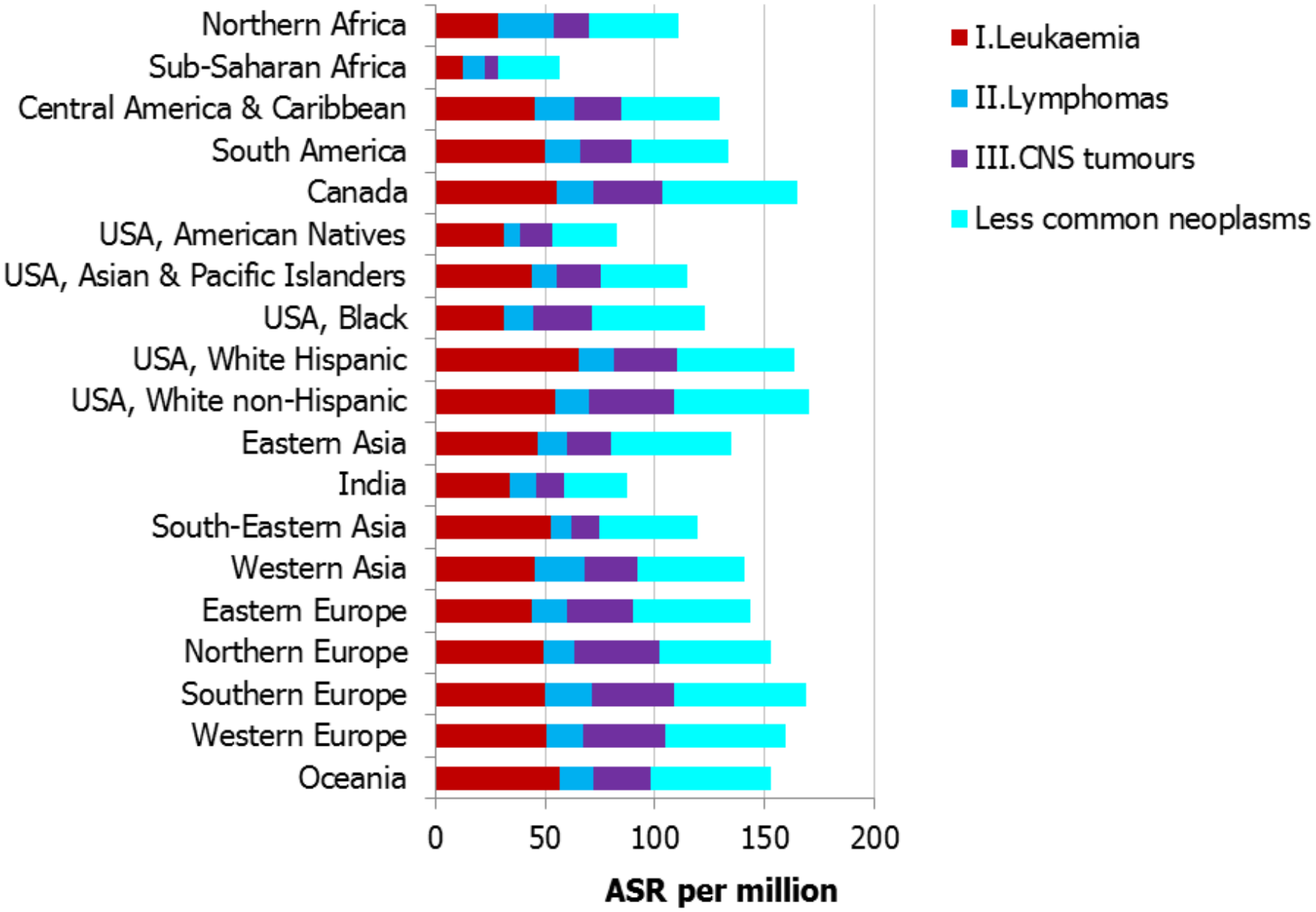
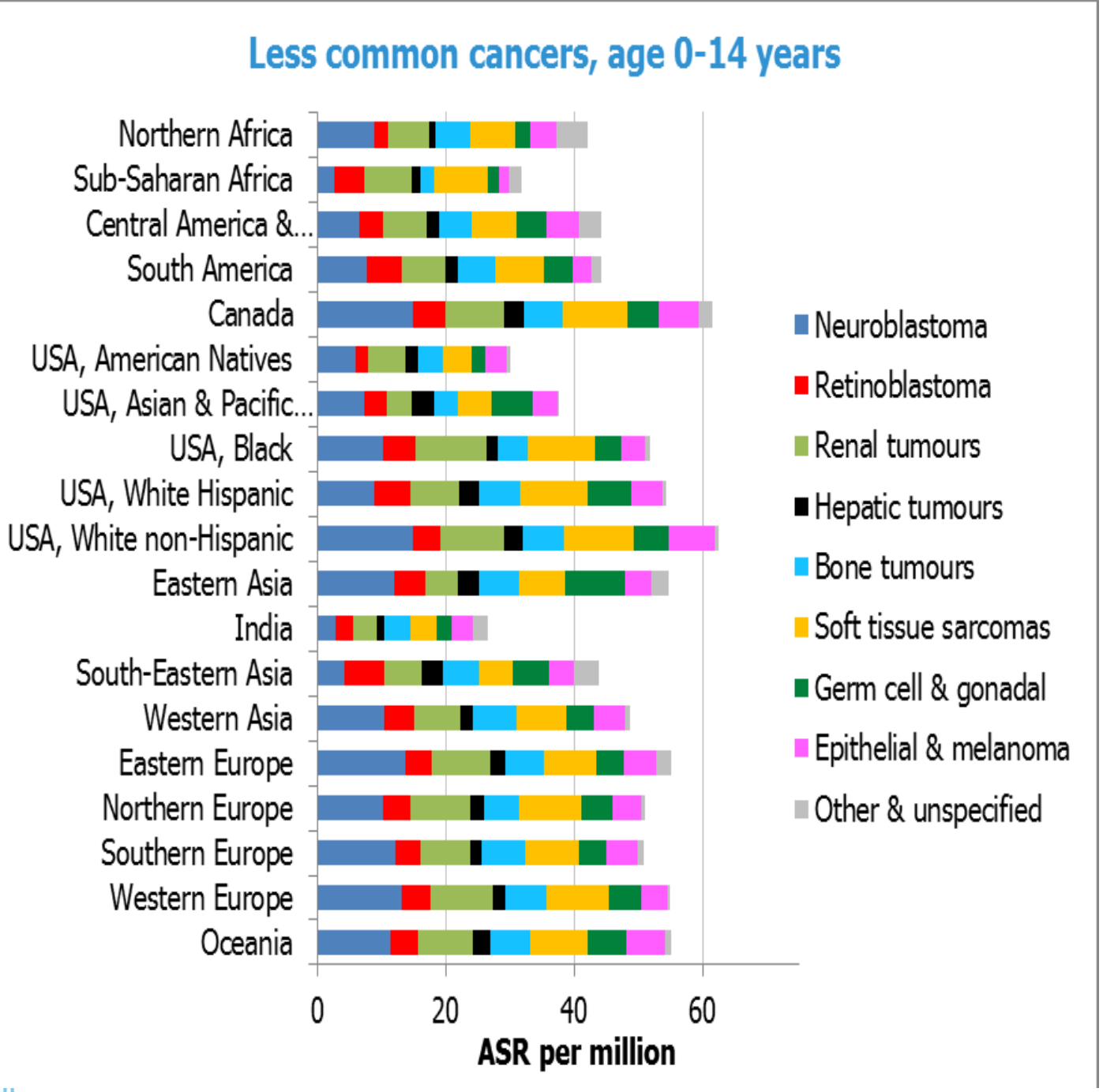
La Vecchia et al., Cancer 1998

All neoplasms, age 0-14 years



World Health Organization

Steliarova-Foucher et al., 2017, Lancet Oncol



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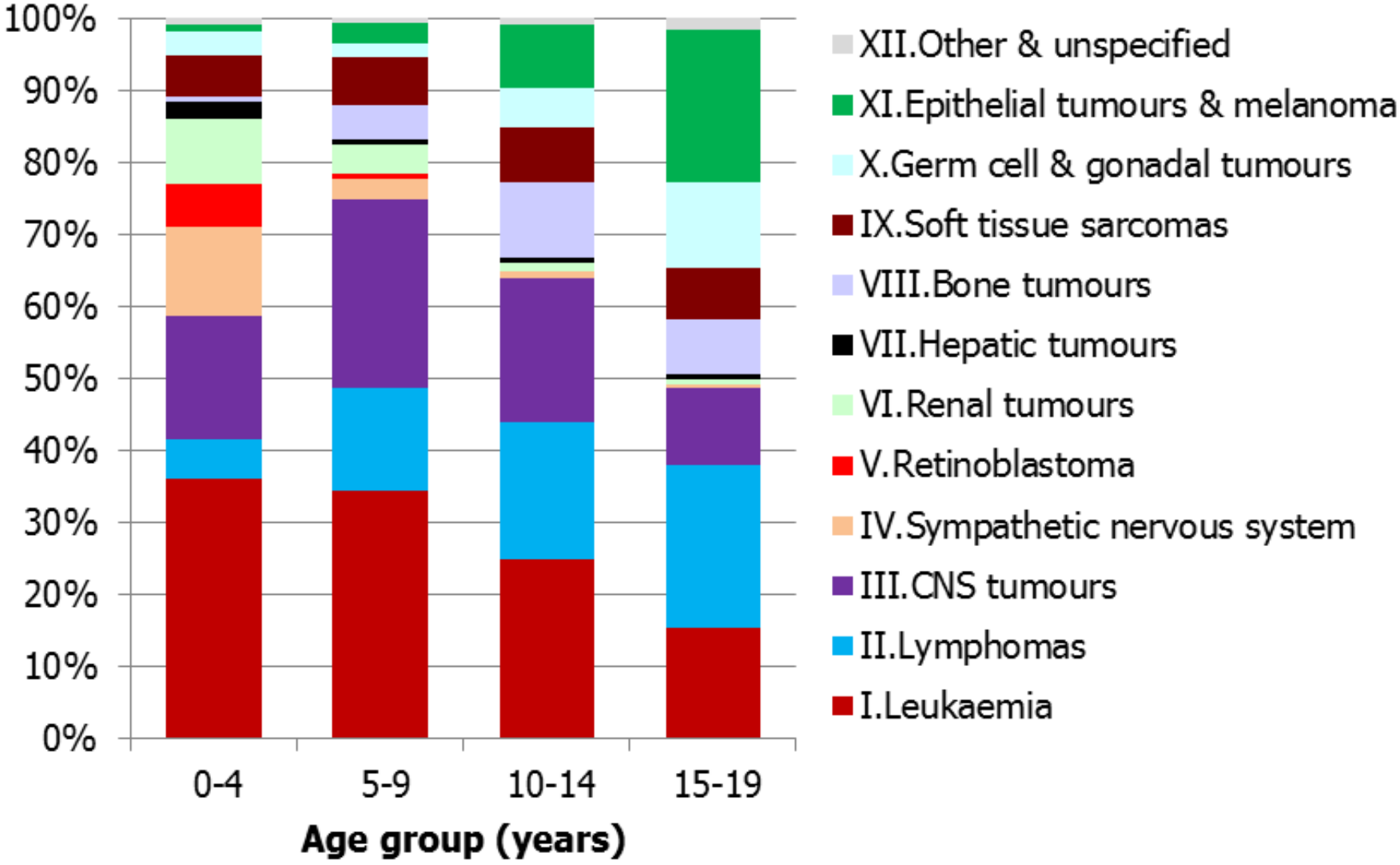
Steliarova-Foucher et al., 2017, Lancet Oncol

Cancer in adolescents

- Age 15-19 (?)
- Some common childhood cancers peak in the age group 15-19 years
- ICCC-3 may be adapted to presentation
- Common treatment strategy
- Awareness of cancer in this age group
- Considered jointly within ACCIS and SEER publications

Distribution of tumour types by age



Steliarova-Foucher et al., 2017, Lancet Oncol

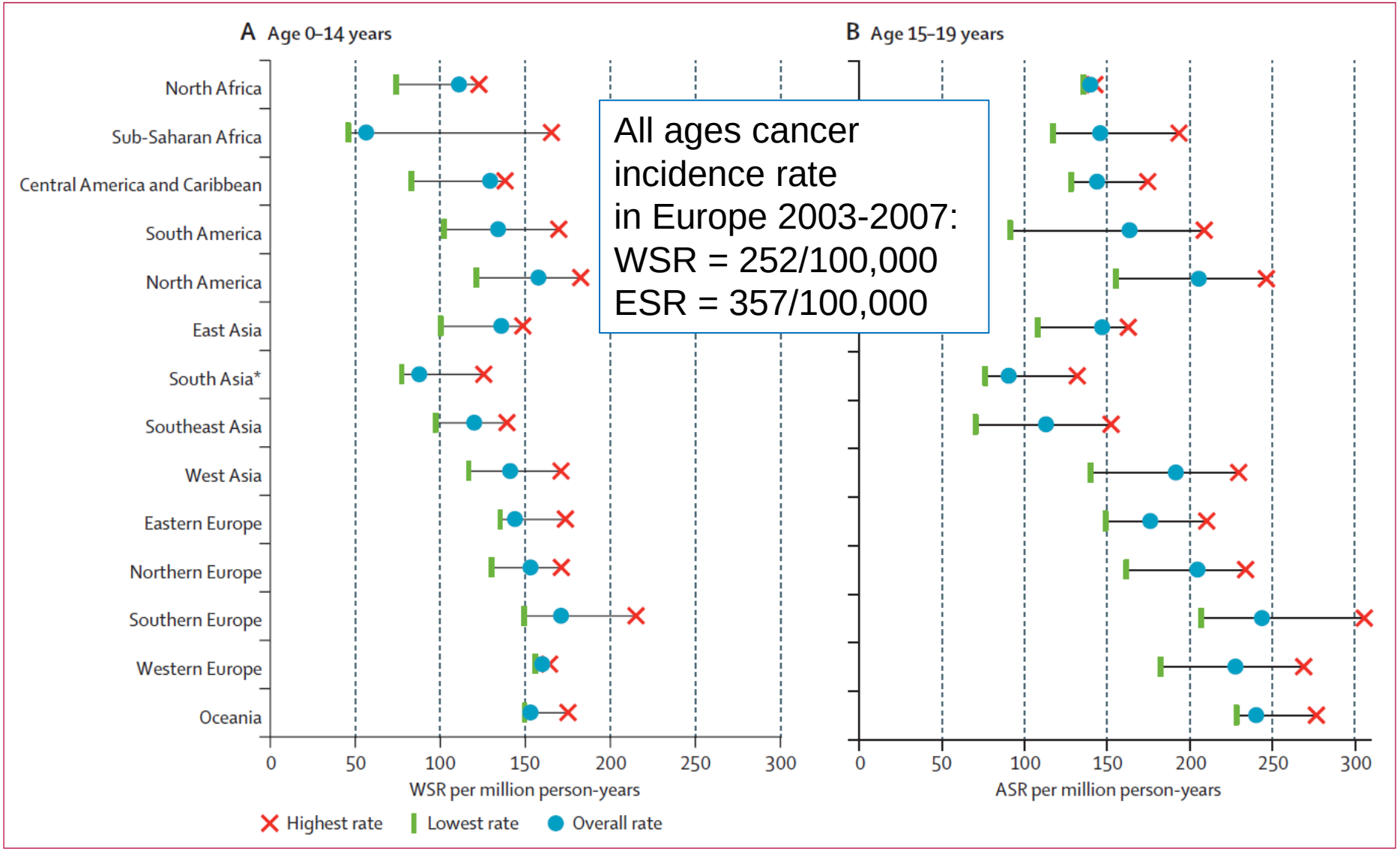
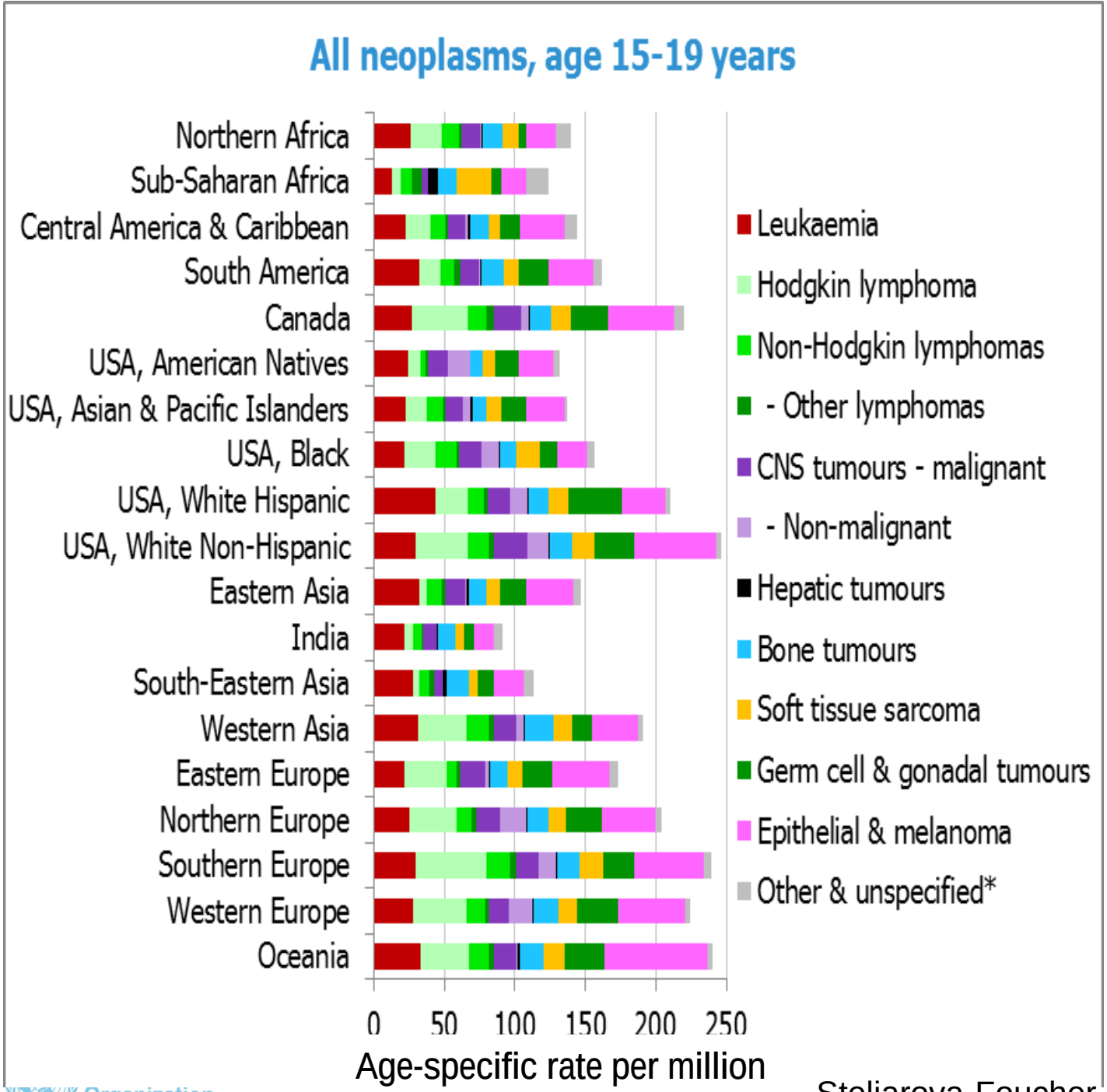


Figure 1: **Variation in the overall incidence of childhood cancer by geographical region, 2001–10**
Data are for children aged 0–14 years, from the paediatric dataset (A), and 15–19 years, from the general dataset (B). We only included registries with more than 100 cases when assessing the lowest and highest rates. ASR=age-specific rate. WSR=age-standardised rate (world standard population). *Comprising data from India only.

Steliarova-Foucher et al, 2017 Lancet Oncol

Steliarova-Foucher et al., 2012, European Cancer Observatory

World Health Organization



Steliarova-Foucher et al, 2017 Lancet Oncol

Cancer survivors

- 1/1000 persons aged 20-29 yrs = survivor of malignant disease before age 20 years
- More than 20 million cancer survivors to be living in the USA by 2026

Alessi et al., 2007 Eur J Cancer

Miller et al., 2016 CA Cancer J Clin

Survivors of cancer in childhood or adolescence

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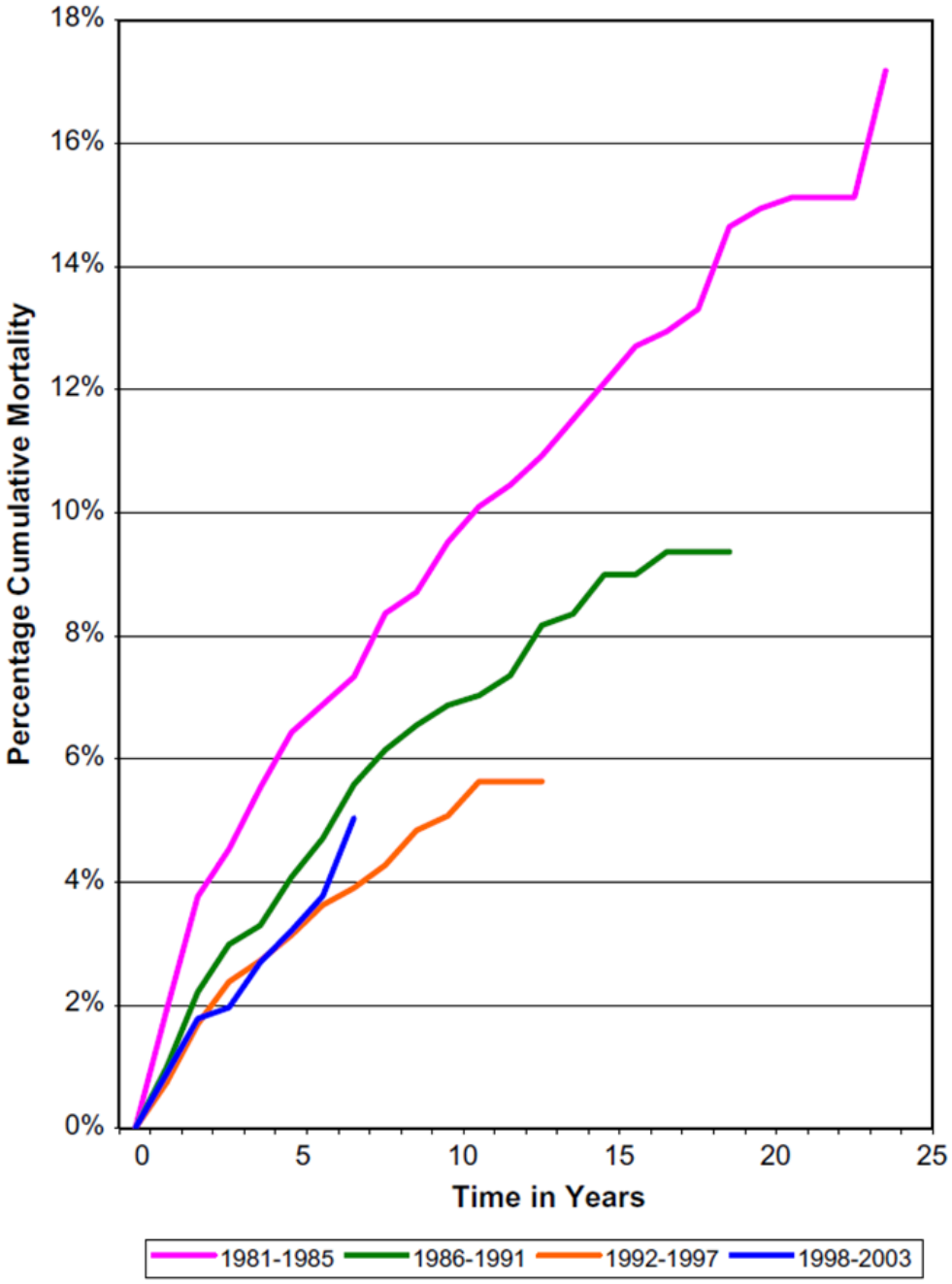
http://www.pancaresurfup.eu/

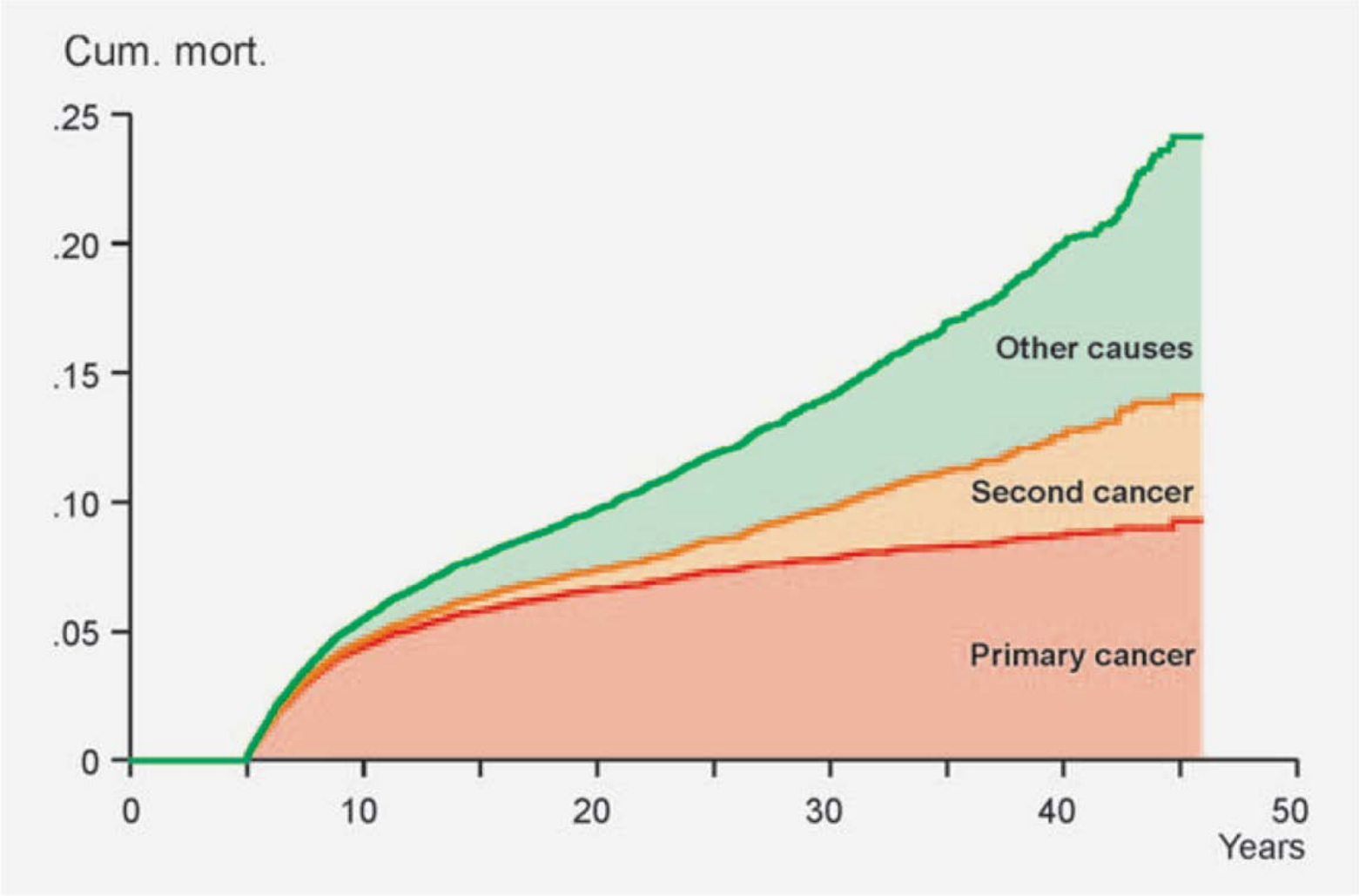
http://www.pancare.eu/en/

Cumulative mortality among five-year survivors diagnosed at ages 0-24 years in Scotland by period of diagnosis of first cancer.



Brewster et al., 2013, Eur J Cancer

Cumulative mortality in 5-year survivors of cancer diagnosed before the age of 20 years in the Nordic countries during 1960-1999



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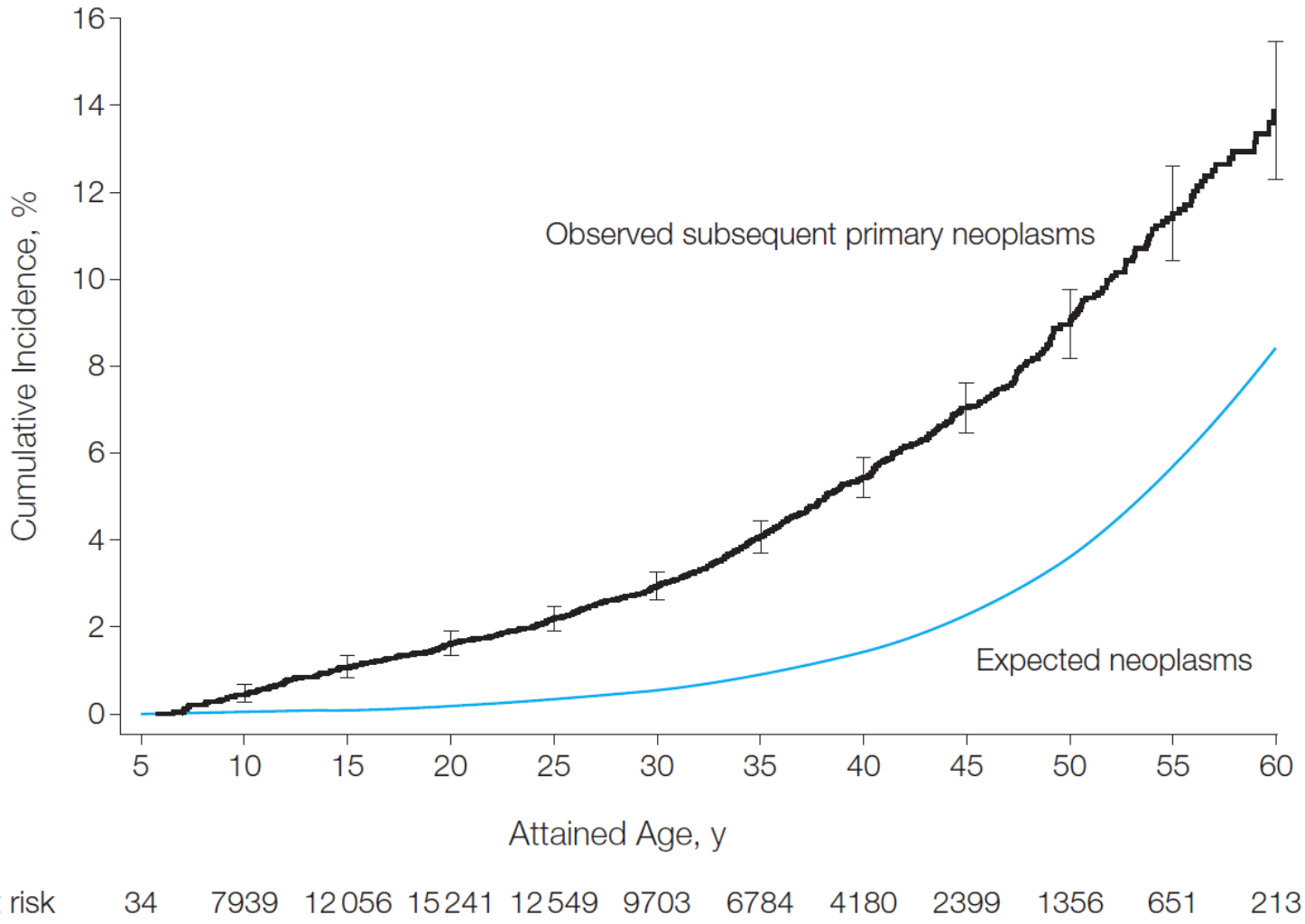
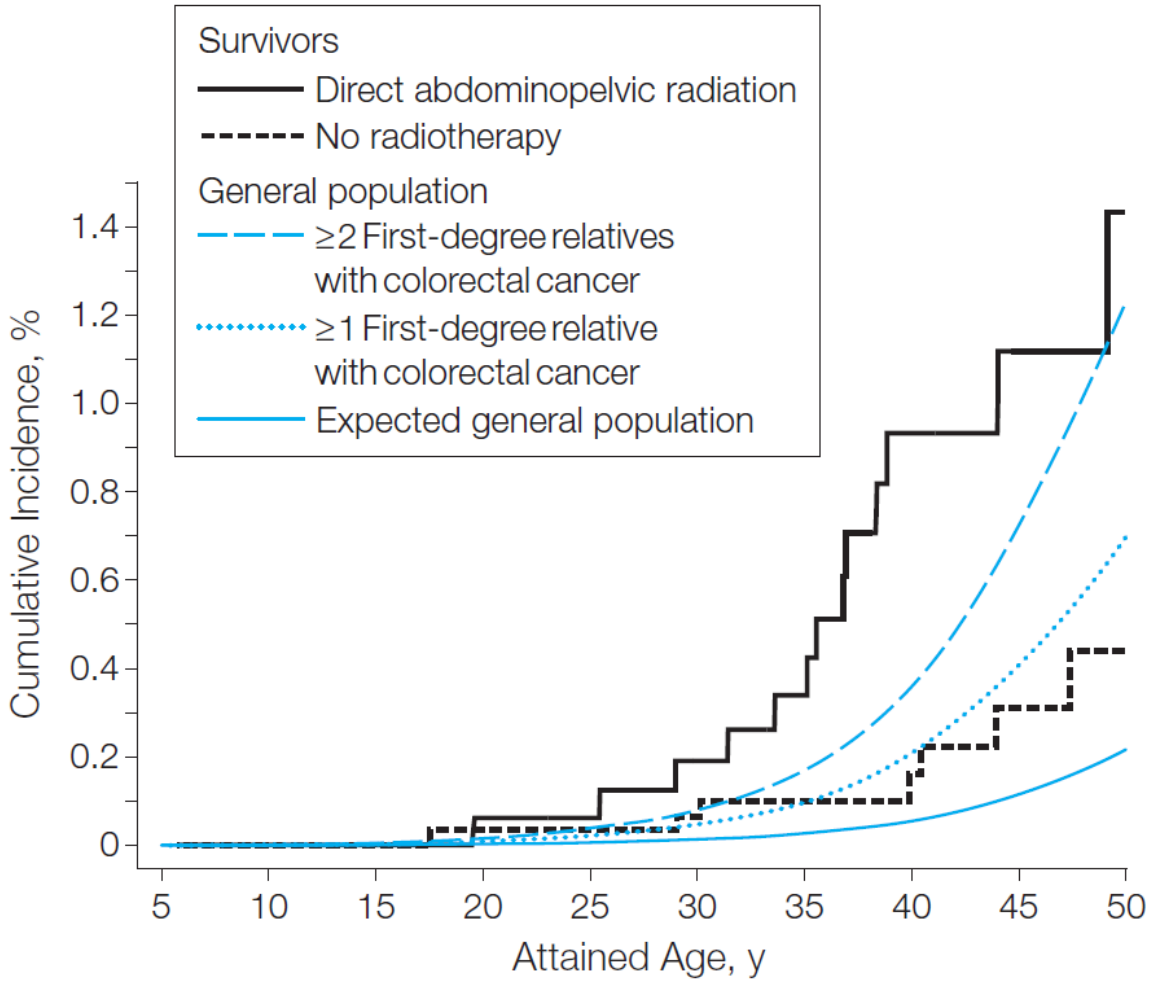
Garwicz et al., 2012, IJC

Observed cumulative incidence of a subsequent primary neoplasm



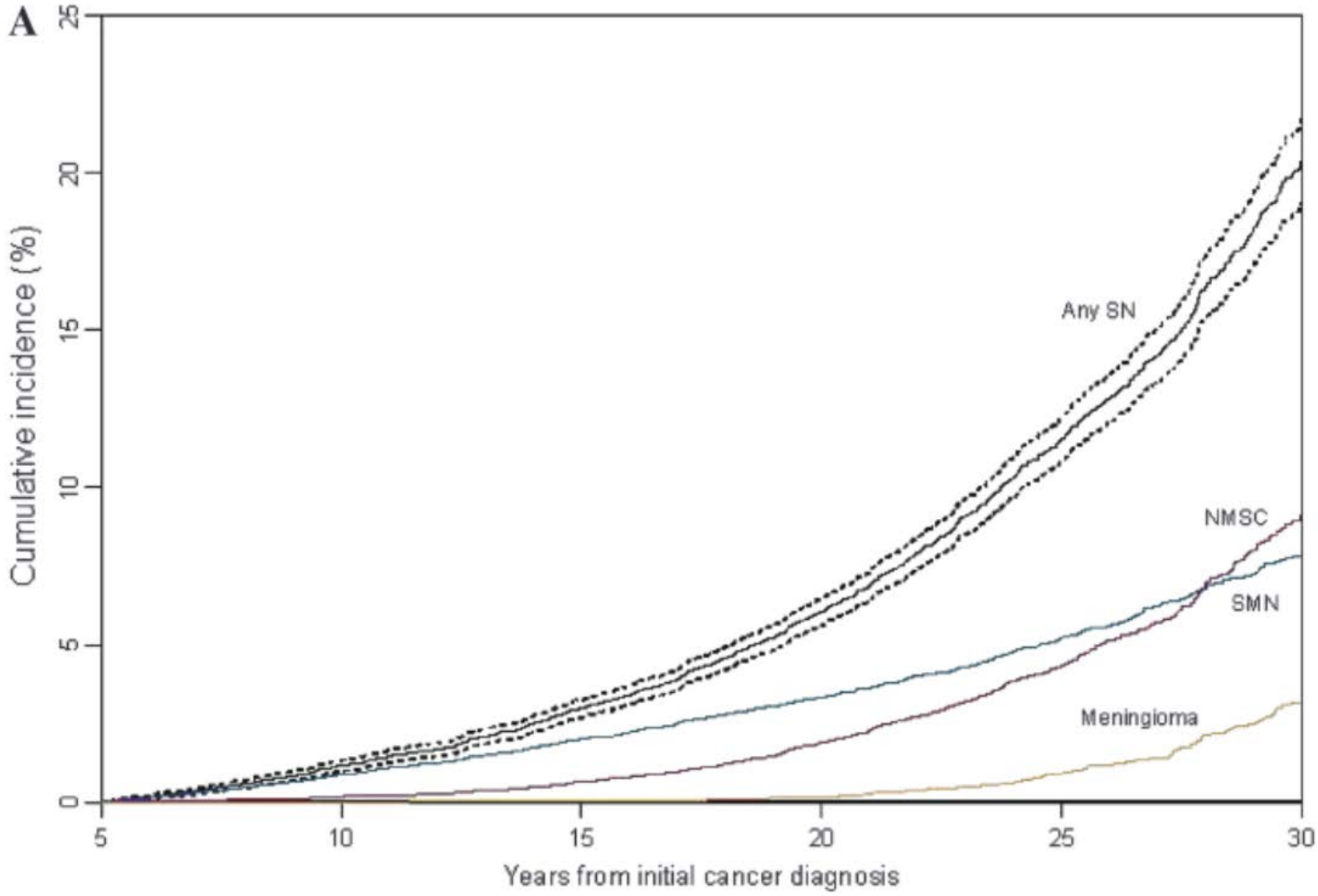
Reulen et al., JAMA, 2011

Cumulative incidence of developing subsequent colorectal cancer for survivors treated with direct abdominopelvic irradiation



Reulen et al., JAMA, 2011

Cumulative incidence of second neoplasms in 5-year survivors of childhood cancer



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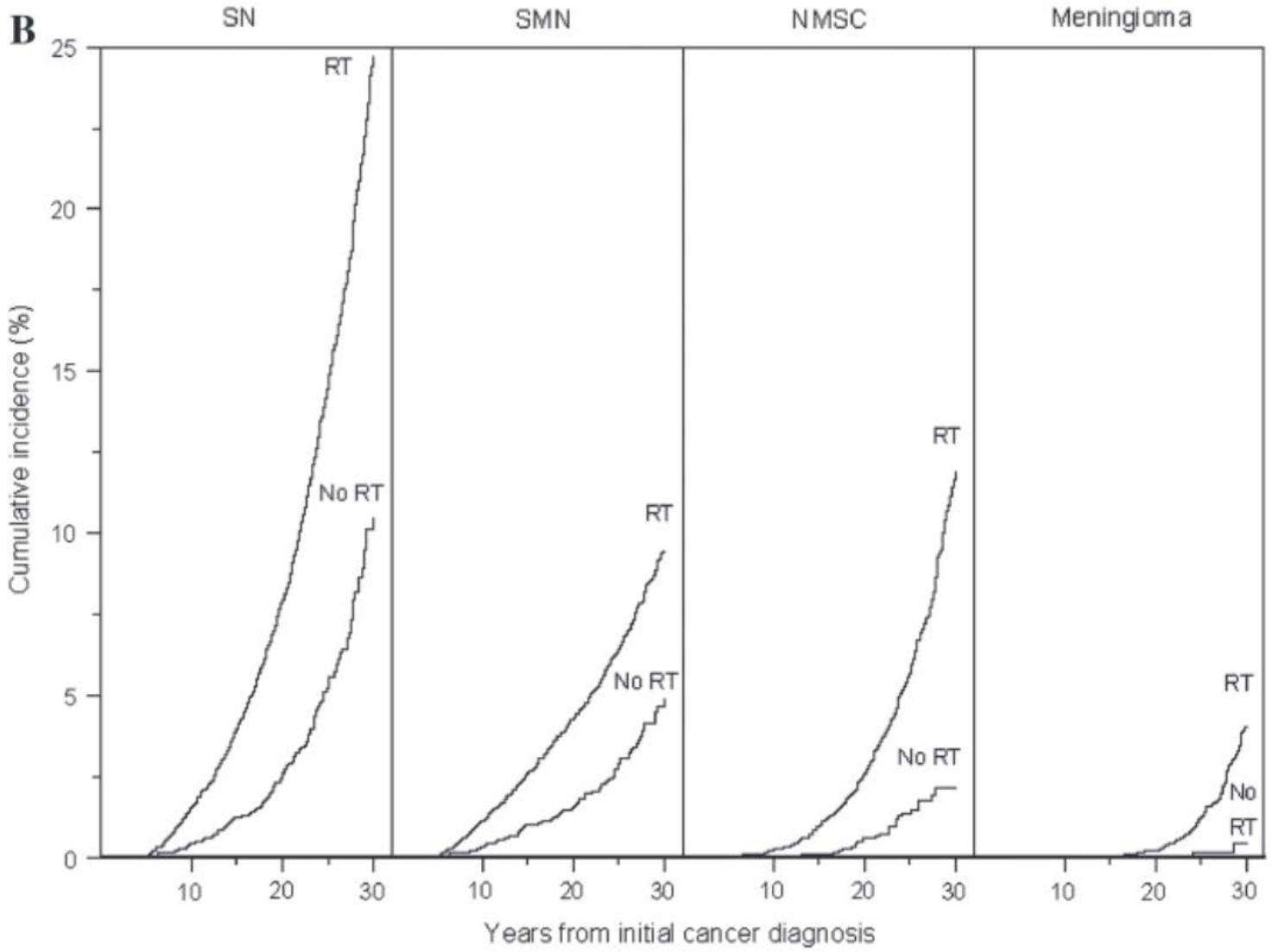
Friedman et al., JNCI 2010

Cumulative incidence of second neoplasms in 5-year survivors of childhood cancer



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Friedman et al., JNCI 2010

Health-related quality of life in 5-year survivors of childhood cancer (age>15 years)

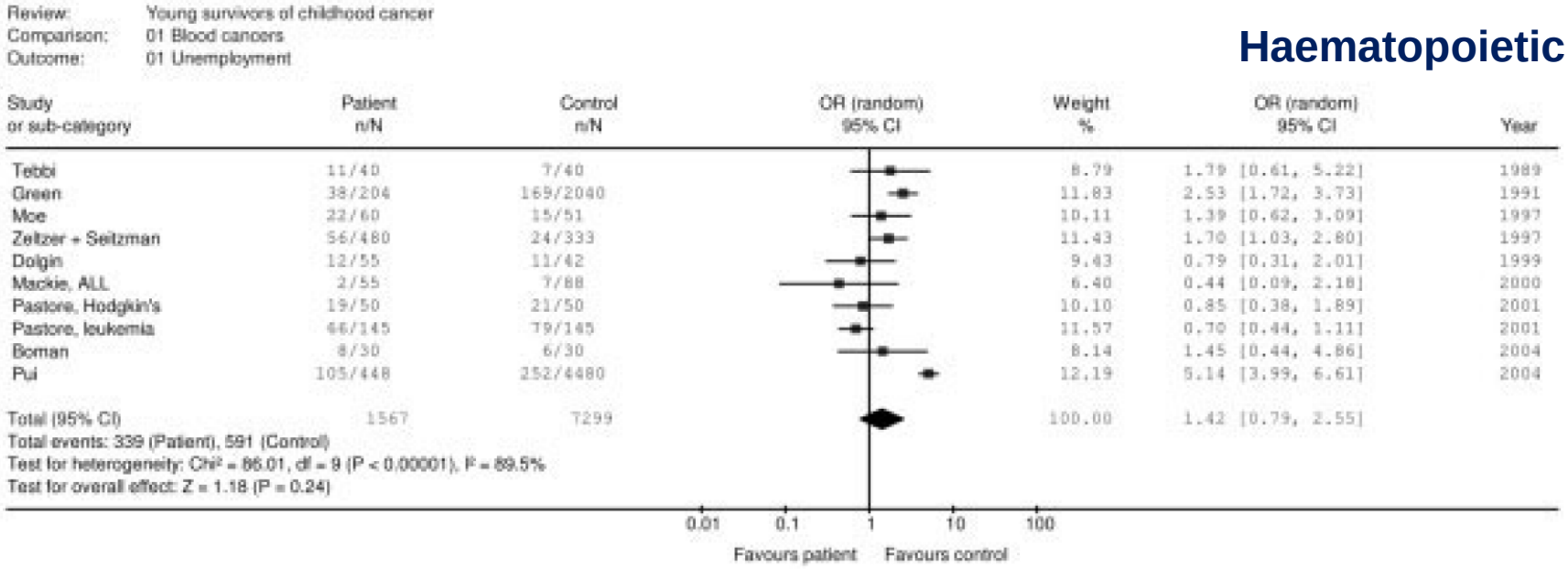
Table 3 – Prevalence odds ratios (PORs) adjusted for all variables in the table and 95% confidence intervals (CIs) for being in the lowest quartile for overall HRQL by survivors' characteristics

Characteristic	Sample size	% in lowest quartile	PORs (95% CIs)
Gender			
Female	295	31.2	1.00
Male	349	19.8	0.51 (0.35–0.74)
Age at diagnosis (years)			
0–4	185	**28.1**	1.00
5–9	200	27.5	0.94 (0.56–1.57)
10–14	259	20.8	0.59 (0.34–1.01)
Cancer type			
Leukaemia	187	20.9	1.00
Non–Hodgkin lymphoma	46	15.2	0.86 (0.35–2.11)
Hodgkin disease	49	14.3	0.86 (0.35–2.13)
Central nervous system tumours	133	36.8	2.48 (1.47–4.18)
Neuroblastoma	35	25.7	1.23 (0.51–2.96)
Retinoblastoma	19	57.9	5.29 (1.89–14.82)
Wilms tumour	42	16.7	0.67 (0.27–1.65)
Bone tumours	31	41.9	3.21 (1.39–7.44)
Soft tissue sarcomas	42	23.8	1.21 (0.54–2.71)
Gonadal tumours	20	20.0	0.94 (0.29–3.04)
All other tumours	40	12.5	0.60 (0.22–1.65)

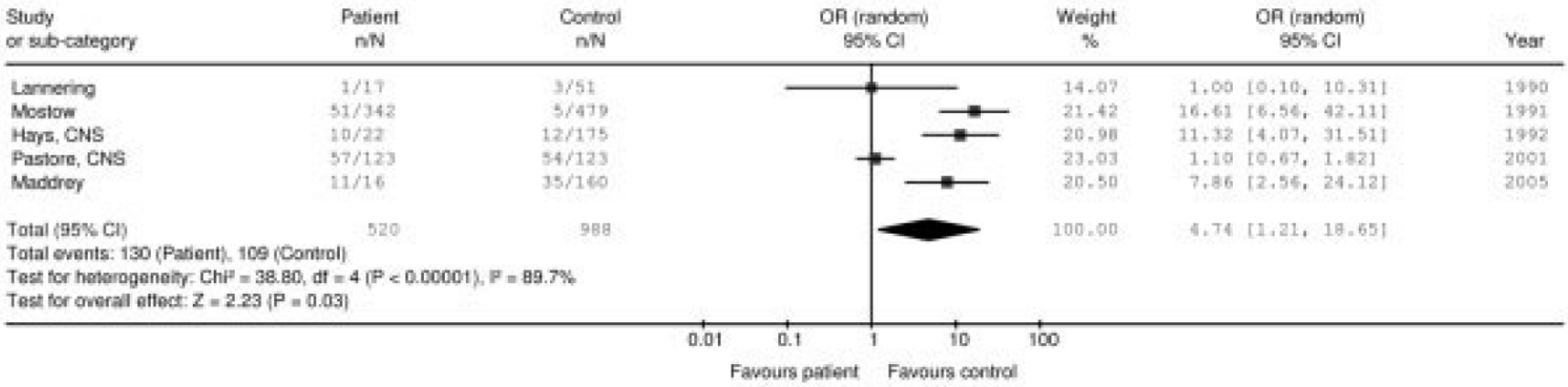
Alessi et al, 2007 Eur J Cancer

Unemployment in young survivors

Haematopoietic



CNS Tumours



De Boer et al., 2006, Cancer

Session 1: Summary
(What do you know about childhood cancer?)

- Rare
- Different from cancers in older ages
- A major cause of death
- Mortality decreasing
- Incidence on a slight increase
- Causes mostly unknown
- Good survival in HIC, bad/unknown in LIC
- Survivorship issues

Session 2

COLLECTION OF DATA ON CHILDHOOD CANCER

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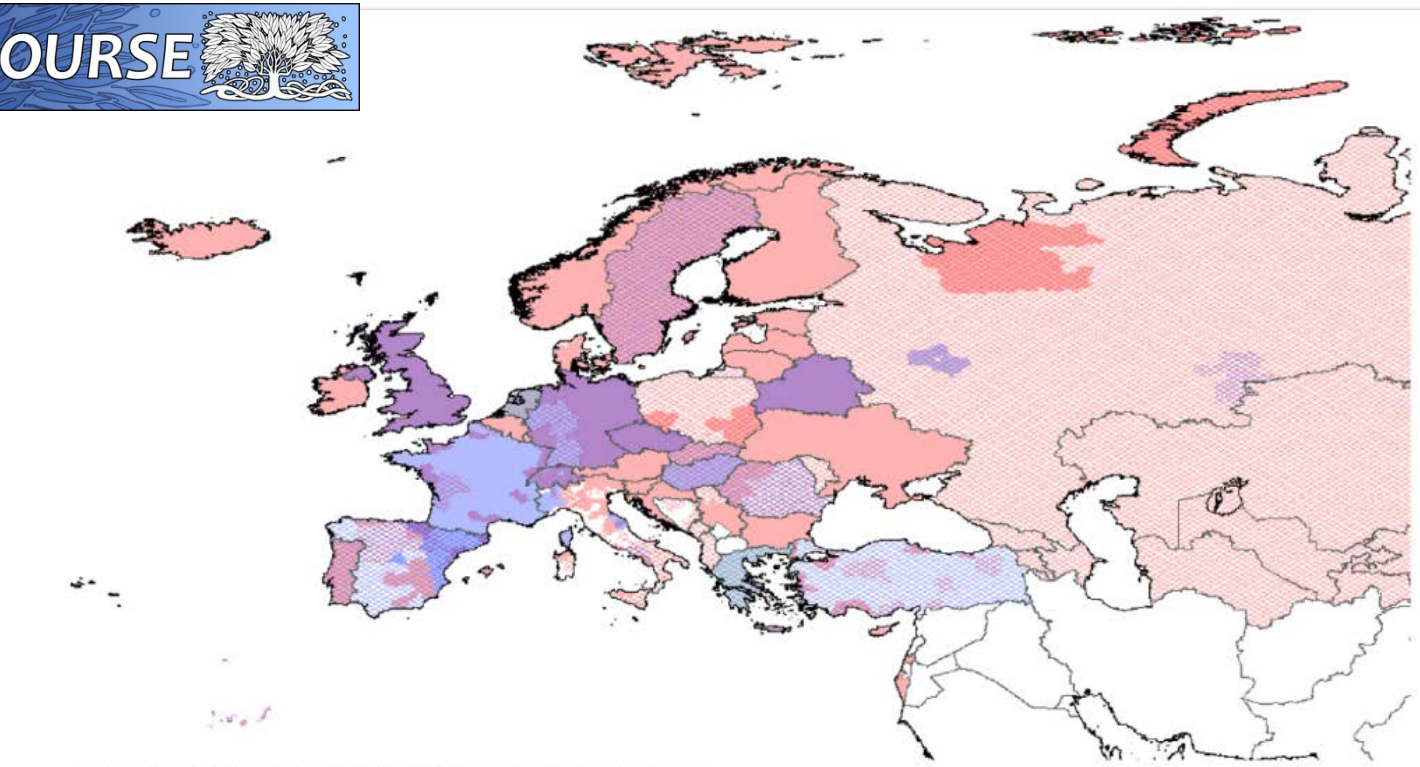
Registration of cancer in childhood

- Age 0-14 (0-19) years at diagnosis

- Specific considerations for data collection, analysis and presentation

(Potential) cancer registration coverage in Europe



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

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The principal colours and patterns:

- General cancer registry (definite coverage)
- Paediatric cancer registry (definite coverage)
- Paediatric cancer registries - specialised
- General cancer registry (potential coverage)
- Paediatric cancer registry (potential coverage)

The blended colours and patterns:

- General cancer registry and paediatric cancer registry, both definite coverage, overlaid
- General cancer registry with potential coverage and paediatric cancer registry with definite coverage, overlaid
- General cancer registry and specialised paediatric cancer registry, both definite coverage, overlaid
- Paediatric cancer registries with either definite or potential coverage, overlaid
- General cancer registry and paediatric cancer registry, both potential coverage, overlaid
- General cancer registry with definite coverage and paediatric cancer registries with potential coverage, overlaid
- General cancer registry with potential and specialised paediatric cancer registry with definite coverage, overlaid
- General cancer registries with either definite or potential coverage, overlaid

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Steliarova-Foucher et al, 2015 Eur J Cancer

(Additional) data sources

- Haematology laboratories
- Paediatric clinics
- Ophtalmology clinics
- Orthopaedic clinics
- Dermatology clinics
- Neurology clinics
- Treatment migrants

(Additional) data quality requirements

- Completeness
- Accuracy
  - Age
  - ICD-O-coding
  - Laterality
- Classification (ICCC)
- Population data

Additional / refined variables

- Pre-existing background
  - Congenital anomaly
  - Predisposing syndrome
  - Other significant condition
  - Cancer in family - member
  - Cancer in family - type
  - Coding system
- Further diagnostic details
  - Stage
  - FAB
  - Cytogenetics
  - Immunophenotype
  - Molecular biology
  - Biological markers
  - WBC count
  - Tumour volume
- Treatment
  - Risk classification (Cytogenetics)
  - Risk classification (Pathology)
  - Date treatment started
  - Clinical trial
  - Randomisation
  - Protocol/Arm
  - Chemotherapy
  - Surgery type
  - Surgery site
  - Immunotheraphy
  - Radiotherapy – type
  - Radiotherapy - dose
  - Radiotherapy - site
  - Radiotherapy - intent

Additional / refined variables

- Medical follow-up
  - Necrosis extent
  - Resection adequacy
  - IRS Post-surgical group
  - Date treatment completed
  - Relapse
  - Date of relapse
  - Site of relapse
  - Blast transformation
  - Progression (relapse)
  - Comorbidity
  - Comorbidity type
  - Hospital admission
- Follow-up for vital status
  - Mode of last contact
  - Health status
  - Place of last residence
  - Cancer as other cause of death
  - Source (cause of death)
- Late sequels
  - Neoplasm
  - Cardiac
  - Urinary
  - Skeletal
  - Endocrine
  - Sense organs
  - QoL

Long-term follow-up data collection

- VERY important for the survivors
- Registries first need to resolve feasibility
- Unlikely successful in regional CR
- International standard not defined (yet)
- Pilot under way
- May vary according to a study aim

Cancer stage

- Informs cancer management, research and information exchange
- Comparison of outcome
- To tackle late presentation/diagnosis

Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

- Stage should be routinely collected for childhood cancers
- TNM generally not applicable to paediatric cancers
- For cancers occurring in children and adults common staging system (eg lymphomas, gonadal cancers)
- Stage should reflect the extent of disease
- Simple, informative international
- Clinical staging important
- Pathological staging for some malignancies
- Tiered (hierarchical) system
- Staging method used
- Endorsed by the UICC TNM Prognostic Factors Project

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Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

Recommended staging systems for major childhood cancers

- Acute lymphoblastic leukaemia
- Acute myeloid leukaemia
- Chronic myeloid lekaemia
- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- Astrocytoma
- Medulloblastoma/CNS embryonal tumours
- Ependymoma
- Neuroblastoma
- Retinoblastoma
- Wilms' tumour
- Hepatoblastoma
- Osteosarcoma
- Ewing sarcoma
- Rhabdomyosarcoma (RMS)
- Non-RMS soft tissue sarcomas
- Testicular tumours
- Ovarian tumours

Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

	Tier 1 staging system	Tier 2 staging system	Comments
Acute lymphoblastic leukaemia	CNS negative	CNS 1[28]	Collection of testicular involvement not endorsed given rarity and uncertain prognostic value in first presentation disease; white blood cell count at presentation was not considered reflective of stage
	CNS positive	CNS 2	
	CNS positive	CNS 3	
Acute myeloid leukaemia	CNS negative	CNS negative[29]	..
	CNS positive	CNS positive	
Chronic myeloid leukaemia	None	None	No relevant staging system identified or necessary
Hodgkin's lymphoma	Ann Arbor—stage IA/B[30] Ann Arbor—stage IIA/B Ann Arbor—stage IIIA/B Ann Arbor—stage IVA/B	Ann Arbor—stage IA/B[30] Ann Arbor—stage IIA/B Ann Arbor—stage IIIA/B Ann Arbor—stage IVA/B	Used in both adult and paediatric populations; recent proposals in adult populations to move to more simplified limited *vs* advanced staging classifications[31] not yet evaluated in paediatric populations; multi-tiered staging systems deemed not appropriate
Non-Hodgkin lymphoma	Limited	St Jude/Murphy—stage I[32]	Tier 1 advanced stage indicates CNS or bone marrow involvement; although some clinicians will use Ann Arbor staging for non-Hodgkin lymphoma, St Jude/Murphy more often used in paediatric populations; Ann Arbor stage IV will often correspond to Tier 1 advanced stage disease; whether Ann Arbor or St Jude/Murphy staging systems were used by clinicians can be difficult to ascertain from medical charts
	Limited	St Jude/Murphy—stage II	
	Limited	St Jude/Murphy—stage III	
	Advanced	St Jude/Murphy—stage IV	

Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

	Tier 1 staging system	Tier 2 staging system	Comments
Neuroblastoma	Localised	INRGSS—localised L1[33]	MS disease refers to children younger than 18 months with metastases confined to skin, liver, or bone marrow; the first two stages of the Tier 1 system are intended to be simplified proxies of INRGSS L1 and L2 not dependent on adequate assessment of imaging-defined risk factors
	Locoregional	INRGSS—locoregional L2	
	Metastatic	INRGSS—metastatic M	
	INRGSS—MS disease	INRGSS—MS disease	
Wilms' tumour	Localised	Stage I[15]/y-stage I[15]	y designates that staging assessment was performed after neoadjuvant therapy was given, which allows the staging system to accommodate both SIOP and COG/NWTSG-based treatment strategies;[15] in cases of bilateral disease the stage of the most advanced kidney should be recorded
	Localised	Stage II/y-stage II	
	Localised	Stage III/y-stage III	
	Metastatic	Stage IV	
Retinoblastoma	Localised (intraocular)	IRSS stage 0[35]	In keeping with current registry guidelines for retinoblastoma, in cases of bilateral disease the stage of the most advanced eye should be recorded; within IRSS stage 0, group A–E was considered Tier 3 recommendation
	Localised (intraocular)	IRSS stage I	
	Localised (intraocular)	IRSS stage II	
	Regional (orbital or regional lymph nodes)	IRSS stage III	
	Distant (extra-orbital)	IRSS stage IV	
Hepatoblastoma	Localised	Localised	Collection of PRETEXT is a Tier 3 option[36]
	Metastatic	Metastatic	

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Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

	Tier 1 staging system	Tier 2 staging system	Comments
Rhabdomyosarcoma	Localised	TNM stage 1[27]	Rhabdomyosarcoma overall stage incorporates both TNM staging and site of disease; as registries collect primary disease site, overall rhabdomyosarcoma stage may be approximated with either tier staging system; for very high-resourced registries, a Tier 3 system that incorporates site of metastases could be considered
	Localised	TNM stage 2	
	Localised	TNM stage 3	
	Metastatic	TNM stage 4	
Non-rhabdomyosarcoma soft-tissue sarcomas	Localised	TNM stage 1[27]	..
	Localised	TNM stage 2	
	Localised	TNM stage 3	
	Metastatic	TNM stage 4	
Osteosarcoma	Localised	Localised	Although more detailed staging systems exist,[34] their clinical and prognostic value is limited; multi-tiered staging systems were not deemed appropriate; for very high-resourced registries, a Tier 3 system which incorporates site of metastases could be considered
	Metastatic	Metastatic	
Ewing's sarcoma	Localised	Localised	Although more detailed staging systems exist,[34] their clinical and prognostic value is limited; multi-tiered staging systems were not deemed appropriate; for very highly resourced registries, a Tier 3 system incorporating site of metastases may be considered
	Metastatic	Metastatic	

Gupta et al., 2016, *Lancet Oncology*

The Toronto paediatric cancer stage Guidelines

	Tier 1 staging system	Tier 2 staging system	Comments
Testicular	Localised	TNM stage I[37]	Although the Tier 1 and Tier 2 staging systems correlate perfectly, the individual components of TNM staging would not be collected in the Tier 1 system
	Regional	TNM stage II	
	Metastatic	TNM stage III	
Ovarian	Localised	FIGO stage I[38]	..
	Regional	FIGO stage II	
	Regional	FIGO stage III	
Astrocytomas	None	None	No relevant staging system identified or necessary
Medulloblastoma and other CNS embryonal tumours	M0 or localised	M0[11]	Residual disease, defined as >1·5 cm^2 after resection, is an important non-stage prognostic factor and could be considered for collection by appropriately resourced registries[39,40]
	M+ or metastatic	M1	
	M+ or metastatic	M2	
	M+ or metastatic	M3	
	M+ or metastatic	M4	
Ependymoma	M0	M0	Extent of resection, defined as no resection *vs* subtotal *vs* gross total, is an important non-stage prognostic factor and might be considered for collection by appropriately resourced registries
	M+	M1	
	M+	M2	
	M+	M3	
	M+	M4	

Gupta et al., 2016, *Lancet Oncology*

Session 2: Summary

- Large proportion of European childhood population covered by cancer registration
- Special requirements to collect data on cancers in children
- Extended dataset desirable but costly
- Long-term follow-up important for survivors, best ensured by national CR
- Specific staging system for childhood cancers
- International standards for collection of extended dataset in development

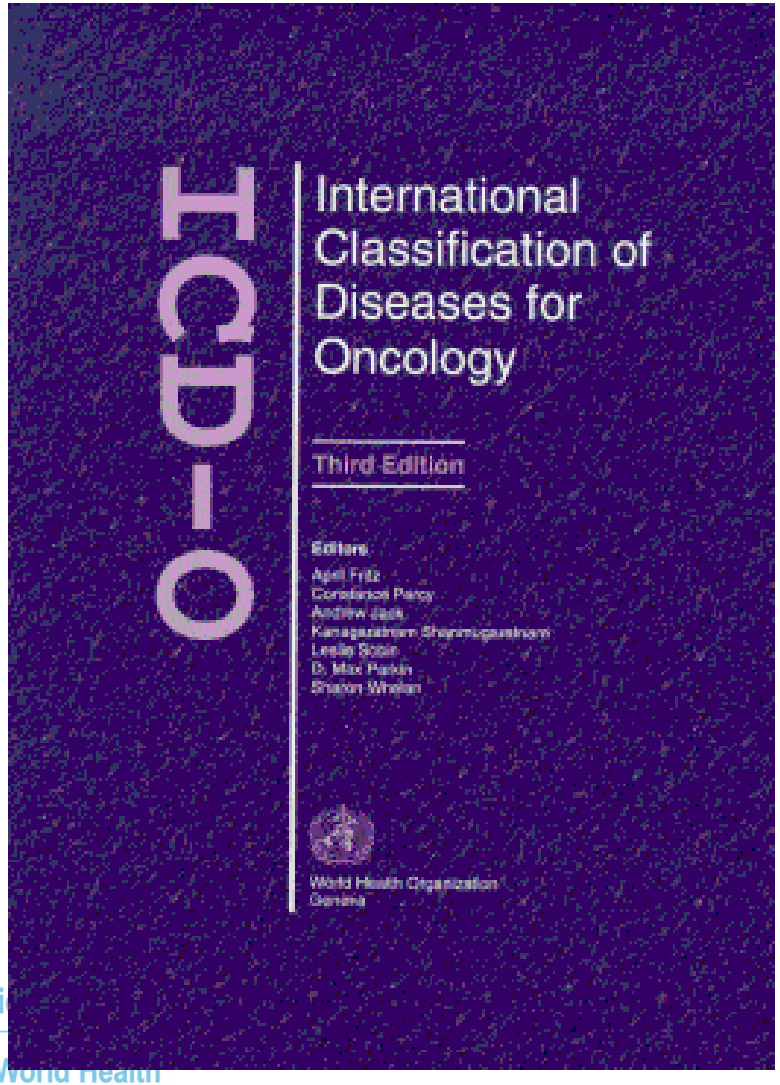
Session 3

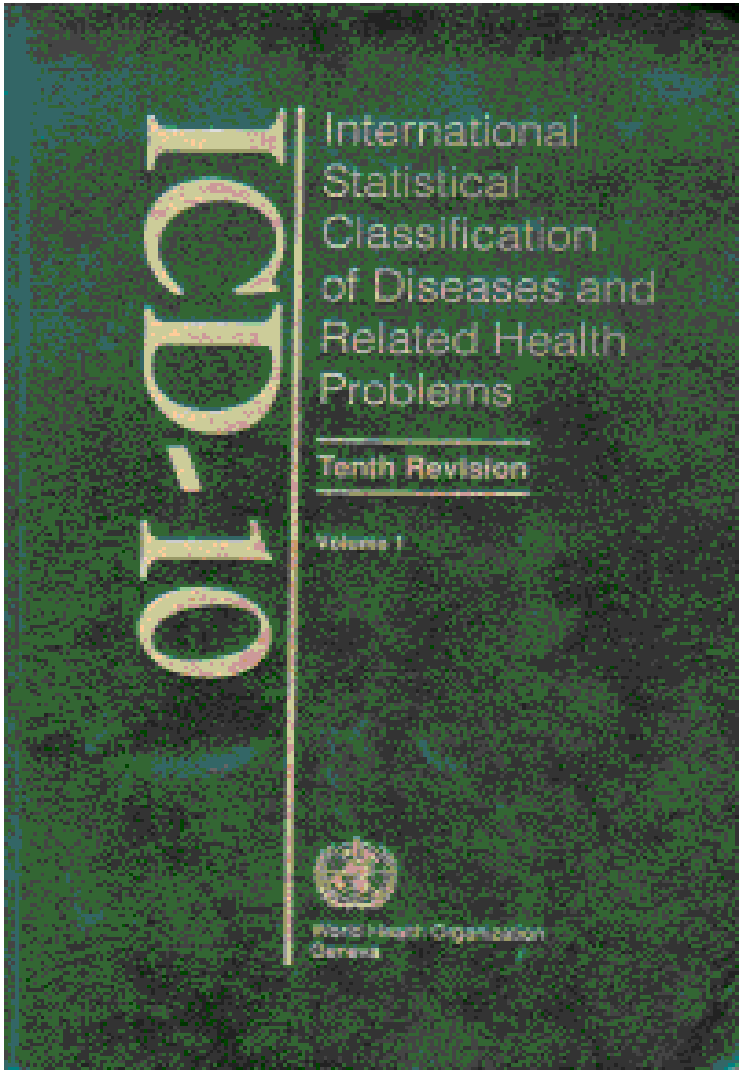
CLASSIFICATION AND DATA QUALITY

International Agency for Research on Cancer

World Health Organization

Classification systems used in cancer registries

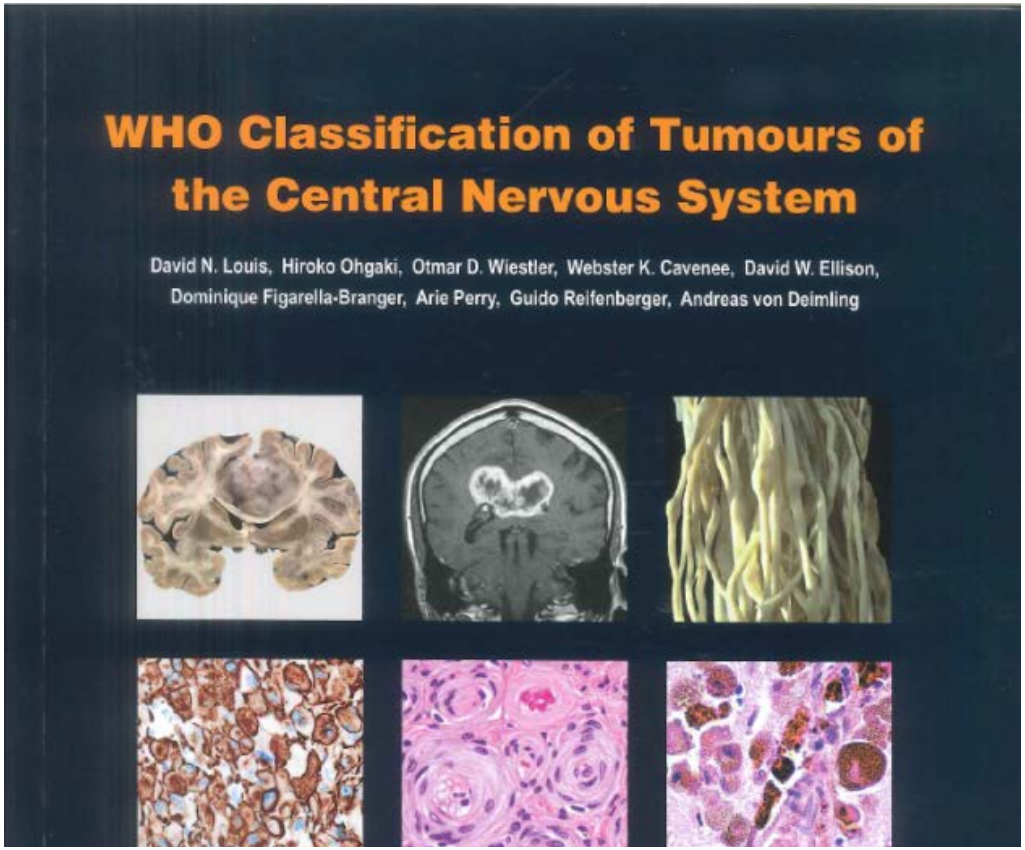




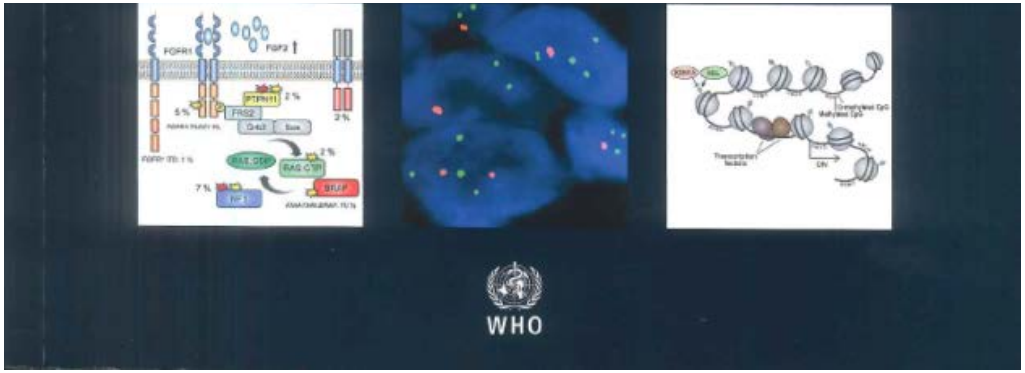
International Histological Classification of Tumours (WHO 'blue books')

- Coordinated by Torloni and Sobin
  - 2nd edition of 14 volumes 1981-1994
- 3rd edition in revised format as the WHO classification of tumours, Pathology and Genetics, coordinated by IARC
  - 20 volumes (2000-2017)

WHO blue books



http://publications.iarc.fr/Book-And-Report-Series/Who-Iarc-Classification-Of-Tumours

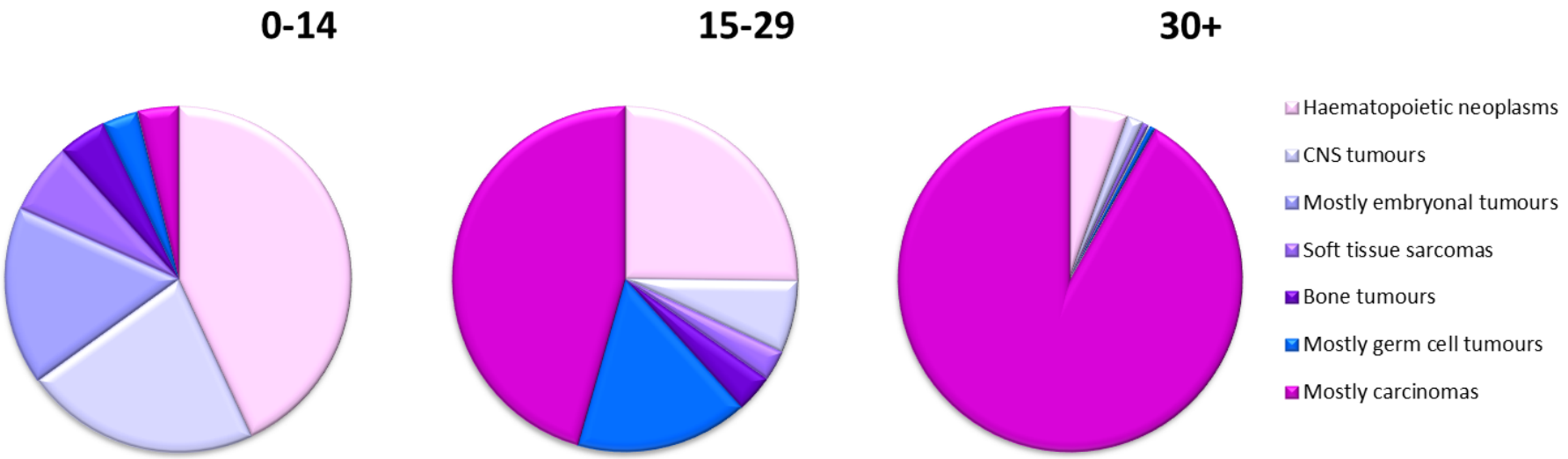


International Agency for Research on Cancer

World Health Organization

Louis et al, 2016, IARC,Lyon

Histology types distribution across the age-range



Source: European Cancer Observatory http://eco.iarc.fr/

Pathological features of cancers in children

- Distinctive morphological appearances
- Resemblance to embryonal tissue
- Absence of precursor lesions
- Occurrence of undifferentiated tumours

Classification of Childhood Cancer

- 1975, Young & Miller, *J Pediatr*
- 1982, Draper et al., HMSO
- 1987, Birch & Marsden, *Int J Cancer*
- 1996, Kramarova & Stiller; *Int J Cancer*
  - IARC Technical Report No. 29
- 2005, Steliarova-Foucher E et al., *Cancer*
  - International Classification of Childhood Cancer, 3rd edition (ICCC-3)
- SOON, ICCC-3 Update

International Classification of Childhood Cancer, edition 3
ICCC-3

1. Classifies tumours using coded nomenclature of the ICD-O-3
2. In conformity with ICD-O, WHO blue books and international literature
3. Reviewed by international authorities in the field
4. Provides continuity with previous childhood classifications, while accommodating new concepts of tumor histogenesis
5. Includes all malignant tumours occurring anywhere in the body AND non-malignant intracranial and intraspinal tumors
6. Exhaustive: includes all tumour types
7. Assumes correct coding
8. Hierarchical system of three levels:
   - 12 main diagnostic groups
   - 47 diagnostic subgroups (11 main groups divided in 2-6 subgroups)
   - 82 divisions (16 subgroups divided in 2-11 divisions)

Main classification table

Extended classification table

Steliarova-Foucher et al., Cancer 2005

Table 1: Main ICCC-3

Diagnostic group		ICD-O-3 codes	
		Morphology	Topography
I	**LEUKAEMIAS, MYELOPROLIFERATIVE AND MYELODYSPLASTIC DISEASES**		
(a)	Lymphoid leukaemias	9820, 9823, 9826, 9827, 9831-9837, 9940, 9948	
(b)	Acute myeloid leukaemias	9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931	
(c)	Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960-9964	
(d)	Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989	
(e)	Unspecified and other specified leukaemias	9800, 9801, 9805, 9860, 9930	
II	**LYMPHOMAS AND RETICULOENDOTHELIAL NEOPLASMS**		
(a)	Hodgkin lymphomas	9650-9655, 9659, 9661-9665, 9667	
(b)	Non-Hodgkin lymphomas (except Burkitt lymphoma)	9591, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698-9702, 9705, 9708, 9709, 9714, 9716-9719, 9727-9729, 9731-9734, 9760-9762, 9764-9769, 9970	
(c)	Burkitt lymphoma	9687	
(d)	Miscellaneous lymphoreticular neoplasms	9740-9742, 9750, 9754-9758	
(e)	Unspecified lymphomas	9590, 9596	
III	**CNS AND MISCELLANEOUS INTRACRANIAL AND INTRASPINAL NEOPLASMS**		

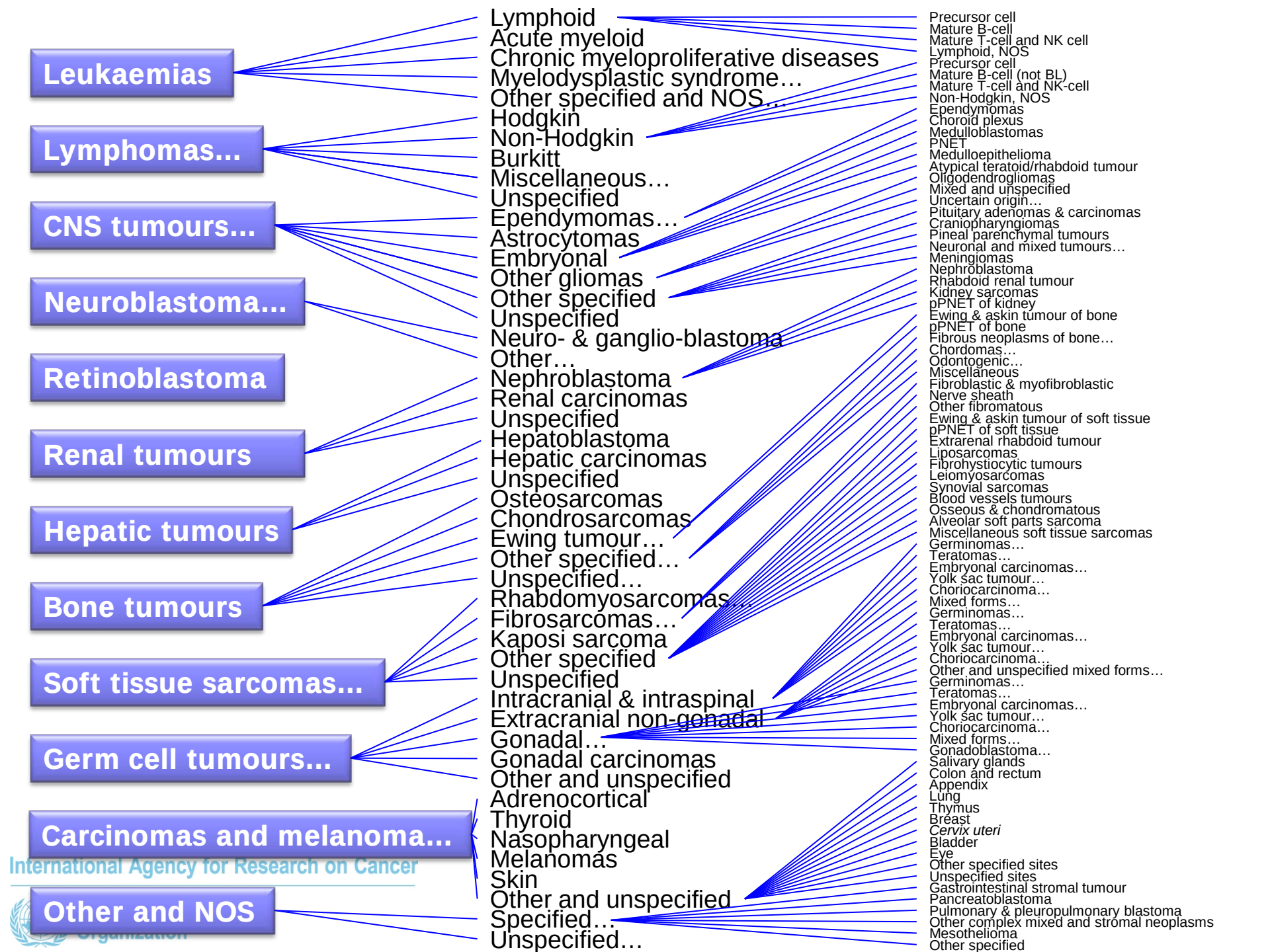
Table 1: Main ICCC-3

	Diagnostic group	ICD-O-3 codes		
		Morphology		Topography
III	**CNS AND MISCELLANEOUS INTRACRANIAL AND INTRASPINAL NEOPLASMS**			
(a)	Ependymomas and choroid plexus tumour	9383, 9390-9394	*	
(b)	Astrocytomas	9380	*	C72.3
		9384, 9400-9411, 9420, 9421-9424, 9440-9442	*	
(c)	Intracranial and intraspinal embryonal tumours	9470-9474, 9480, 9508	*	
		9501-9504	*	C70.0-C72.9
(d)	Other gliomas	9380	*	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
		9381, 9382, 9430, 9444, 9450, 9451, 9460	*	
(e)	Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9412, 9413, 9492, 9493, 9505-9507, 9530-9539, 9582	*	
(f)	Unspecified intracranial and intraspinal neoplasms	8000-8005	*	C70.0-C72.9, C75.1-C75.3
IV	**NEUROBLASTOMA AND OTHER PERIPHERAL NERVOUS CELL TUMOURS**			
(a)	Neuroblastoma and ganglioneuroblastoma	9490, 9500		
(b)	Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523		
		9501-9504		C00.0-C69.9, C73.9-C76.8, C80.9

continued

Table 2: EXTENDED ICCC-3

ICCC-3 division			ICD-O-3		
			Morphology		Topography
Ia. Lymphoid leukaemias					
	1	Precursor cell leukaemias	9835, 9836, 9837		
	2	Mature B-cell leukaemias	9823, 9826, 9832, 9833, 9940		
	3	Mature T-cell and NK cell leukaemias	9827, 9831, 9834, 9948		
	4	Lymphoid leukaemia, NOS	9820		
IIb. Non-Hodgkin lymphomas					
	1	Precursor cell lymphomas	9727, 9728, 9729		
	2	Mature B-cell lymphomas (except Burkitt lymphoma) ✧	9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698, 9699, 9731-9734, 9761, 9762, 9764-9766, 9769, 9970		
	3	Mature T-cell and NK-cell lymphomas	9700-9702✦, 9705, 9708, 9709, 9714, 9716-9719, 9767, 9768		
	4	Non-Hodgkin lymphomas, NOS	9591, 9760		
IIIa. Ependymomas and choroid plexus tumour					
	1	Ependymomas	9383, 9391-9394	✸	
	2	Choroid plexus tumour	9390	✸	
IIIc. Intracranial and intraspinal embryonal tumours					
	1	Medulloblastomas	9470-9472, 9474, 9480	✸	
	2	Primitive neuroectodermal tumour (PNET)	9473	✸	
	3	Medulloepithelioma	9501-9504	✸	C70.0-C72.9
	4	Atypical teratoid/rhabdoid tumour	9508	✸	
IIId. Other gliomas					
	1	Oligodendrogliomas	9450, 9451, 9460	✸	
	2	Mixed and unspecified gliomas	9380	✸	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
			9382	✸	
	3	Neuroepithelial glial tumours of uncertain origin	9381, 9430, 9444	✸	



Purpose of ICCC-3

- To ensure that comparable information is available for research, planning, implementation and evaluation of cancer control measures on local and international level

ICCC-3 non-classifiable records

- Non-malignant tumours in non-CNS sites
- Cases with behaviour code 6 or 9
- Coding errors
- Classification gaps

- See document ‘ICCC-3 unclassifiable records’, downloadable from ‘Links’ section of the Registries Portal at https://cinportal.iarc.fr

International standards for cancer registries

- IACR/ENCR 1995-2002
  - Date of incidence
  - Multiple primaries
  - Bladder tumours
  - Tumours of the brain & CNS
  - Basis of diagnosis
  - Automated CR
  - Non-melanoma skin cancers
  - Method of detection in relation to screening
  - Extent of disease (Condensed TNM)
  - Leukaemia & lymphoma
  - Structured registry reviews
  - Confidentiality in cancer registration
- EUROCOURSE (2009-2012)
  - Ethics & Confidentiality in cancer registration Registration of information related to screening
  - Registration of information related to biobanking
  - Rules for registration of haematological malignancies
  - 10 commandments on governance for program owners
- JRC/ENCR (2014)
  - Quality check harmonisation

ICCC-3: Summary I

- ICD-O series best adapted to cancer registration
  - 3rd Edition in current use
- ICD system
  - Causes of death coding
  - Presentation of cancer statistics in all ages or adults
  - Not suitable for presentation of childhood cancer
  - 10th Revision in current use
- WHO classification
  - Histological typing of tumours
  - 3rd and 4th Edition in current use

ICCC-3: Summary II

- ICCC
  - Based on the ICD-O coded nomenclature of topography, morphology and behaviour
  - Most appropriate for presenting statistics on cancer burden in children & suitable also for 15-19 age group
  - ICCC-3 in current use
  - ICCC-3 Update coming soon

Session 4

INTERACTIVE EXERCISE 6: EVALUATION OF CHILDHOOD CANCER DATASET

International Agency for Research on Cancer

World Health Organization

Exercise 6: dataset evaluation

- Group work
  - 5 groups
  - 5 presenters minimum
- Available files:
  - Report
  - Summary
  - Population
- Working time
  - 15 minutes
- Expected output:
  - 2-minutes presentation
  - Decision about non/comparability (IICC-3 ex/inclusion)
  - Justification